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# Inclusion or Illusion?

Policies and practices for children with  
disabilities and their families in Bosnia &  
Herzegovina and Bulgaria

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BSc (Westminster), MPhil (Cambridge)

A thesis submitted in partial fulfilment of the  
requirements of the Open University for the degree of  
Doctor of Philosophy

Social Policy and Sociology

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## ABSTRACT

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This study examines the social exclusion of disabled children and their families in Bosnia & Herzegovina and Bulgaria and aims to identify opportunities for and obstacles to social inclusion. Both countries have experienced major socio-political and economic changes associated with the transition from communism to an open market economy and democracy. They are in the process of aligning their policies and practices to a European Union favoured agenda of social inclusion and human rights. The thesis identifies key professional practices and views towards disability which are persistent and constitute major obstacles to inclusion. On the other hand a number of opportunities for inclusion have been identified in the processes of policy reform, parents' activism and the development of community care. The study also explores how current international pressures originating from supranational and international agencies, such as the European Union, World Bank and International Monetary Fund support or hinder inclusion efforts. The thesis explores the complexity of inclusion and it provides an understanding of the extent to which the idea is an illusion when it is not fully embraced by the stakeholders and countries concerned. This qualitative research reports and analyses the views of a variety of actors; children with disabilities and their parents, professionals who work in residential institutions and special schools, policy makers, social workers and representatives of NGOs and international organizations. These interviews tell the story of how policies and practices affect individual families and children with disabilities and in so doing provides a distinctive critique of the current situation.

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## List of Abbreviations

B&H	Bosnia and Herzegovina
CEE	Central and Eastern Europe
CIS	Commonwealth of Independent States
UNCRPD	United Nations Convention on the Rights of Persons with Disability
EUROSTAT	European Union Statistical Agency
EC	European Commission
EU	European Union
FB&H	Federation of Bosnia and Herzegovina
IMF	International Monetary Fund
IO	International Organisation
IBHI	International Bureau for Humanitarian Issues
INGO	International non-governmental organisation
KM	Konvertibilna marka (Convertible mark, B&H currency)
MDG	Millennium Development Goals
NGO	Non-governmental organisation
OSCE	Organisation for Security and Cooperation in Europe
OECD	Organisation for Economic Cooperation and Development
OMC	Open Method of Coordination
RS	Republika Srpska
SEE	South East Europe
UN	United Nations
UNICEF	United Nations Children's Fund
USAID	US Agency for International Development
UNDP	United Nations Development Programme
WB	World Bank

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## INTRODUCTION

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Human rights organisations have been reporting that children with disabilities in the Region of Central and Eastern Europe are subjected to discrimination, violation of their rights, and high rates of institutionalisation (Save the Children, 2003; UNICEF, 2005; Open Society Institute, 2005). Furthermore in 2005 the UNICEF Innocenti Research Centre published a comprehensive analysis of the situation for children with disabilities in the 27 countries of Central and Eastern Europe (CEE), the Commonwealth of Independent States (CIS) and the Baltic States. The UNICEF research revealed a number of key issues across the region: an increase in child disability, a long standing practice of institutionalizing children with disabilities, a lack of support for families, a lack of knowledge about children's rights and deeply rooted prejudice about disability. However the report revealed that there are also some positive indications; the practice of mainstreaming and including disabled children, adoption of a children's rights perspective and the inclusion of the family as part of a policy solution for disabled children are all currently being employed in those countries.

In 2006 with the adoption of the United Nations' Convention on the Rights of Persons with Disabilities (UNCRPD), a strong message was relayed to governments that disability is not only a welfare, but also a human rights issue. The UNCRPD calls for the commitment to equalise opportunities for disabled people, to reduce all forms of discrimination by making physical and social environments more accessible and to

increase the participation of people with disabilities. This convention also examines the situation of families with children with disabilities, because for the first time through adoption of this convention (article 23), the importance of support that needs to be provided to children with disabilities and their families is acknowledged.

## SIGNIFICANCE OF THE STUDY

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Since the early 90s there has been strong recognition by international organisations working on children's wellbeing that the situation for disabled children and their families in the countries of CEE and CIS needs to be urgently addressed (Burke, 1994; UNICEF, 2005, 2007; Carter, 2005). This study 'Inclusion or Illusion? Policies and Practices for Children with Disabilities and their Families in Bosnia & Herzegovina (B&H) and Bulgaria' responds to this issue. In addition this study comes at a time of major change in disability policies in Eastern Europe and as such it has the potential to inform national policy makers and donors. Furthermore, by employing an in-depth qualitative methodology and including groups usually excluded from the research, this work provides knowledge and understanding that is often missing from policy studies (Manning, 2004; Morris et al., 2009). There is a need to hear the voices of children and parents and to examine not only how new policies affect their lives, but also to understand (from a qualitative perspective) what the key issues are for practitioners and national policy makers. At issue is whether inclusion practices are aligned with policies and embraced by diverse stakeholders. If not, then no matter what claims are

made, any practical benefits for disabled children and their families may be more illusory than real.

The emerging welfare systems in Bosnia and Herzegovina (B&H) and Bulgaria reflect a combination of the strong neo liberal agendas promoted by the World Bank (WB) and International Monetary Fund (IMF) and the state socialist values inherited from previous communist/socialist regimes. With the influence of human rights organisations and drives towards EU accession, serious attempts are being made to reform the system, moving it from an overly medicalised and institutionalised bureaucracy to one focused on human rights and social inclusion. As such the new developments reflect the promotion of a community services and user oriented approach, a striking contrast to the bureaucratised structures and paternalistic values of the old states (Stubbs, 2006).

The EU pre-accession and accession processes bring resources, new ideas, and influences that undoubtedly impact on potential member states. In this respect the situations in B&H and Bulgaria offer unique conditions for examining and observing the effect of diverse influences and values which shape social policies. Policy issues in the region have been subject to scholarly investigation by eminent social policy analysts (Deacon 2000; Lendvai, 2004; Stubbs, 2007; Saurugger & Radaelli, 2008) and national policy discussions, for example IBHI (2007). The current work, with its comparative focus on two countries, adds to this important body of literature and



contributes to the debates concerning the exclusion and inclusion of disabled children and their families.

In examining the social policy changes in Eastern Europe Manning (2004) argues that the policy debates have been based on formal government legislation, whilst the opinions and views of those who either implement policy or are at the receiving end of policy appear largely absent. This study aims to address that gap in B&H and Bulgaria, by representing the views of service users and professionals throughout the thesis and by utilising these views in the production of policy and practice recommendations. The study also provides insight into the way international organisations exert specific pressures related to financing and adoption of political agendas in countries which are heavily dependent on international support.

My interest in doing this research emerged as a combination of professional and personal experiences. In 1992 with the onset of war in Bosnia and Herzegovina I became a refugee and started to experience discrimination on many levels, but never tried to understand and deconstruct this experience. When I graduated in psychology in 1999 in London I went back to Bosnia and worked in mental health services with refugees and displaced people. They were suffering from a combination of severe war traumas and post-war marginalisation because of displacement and poverty. Several years later my professional career led me to work with disadvantaged children and young people who were outside education because they were very poor, or disabled or belonging to the Roma minority. When I came back to England to do my Masters'

degree in inclusive education I got introduced to the ideas of social and education exclusion and the social model of disability. This prompted me to engage more deeply with these concepts and ideas in trying to understand the situation of children with disabilities in Eastern Europe.

## RESEARCH AIM AND OUTCOMES

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The aim of this thesis was not to investigate particular impairments and specific issues related to them. Rather, the aim is to conduct a broad investigation concerning the general approach of the state, national and international policy makers, NGO workers, professionals and users towards the care and support for children with disabilities and their families in B&H and Bulgaria. A unique aspect of this research in B&H and Bulgaria is that it is grounded in examining issues that families with children with disabilities are experiencing i.e. children's disability has been researched in a family context. However it also acknowledged that many disabled children do not live with their families and for this reason the research is also concerned to engage with a diversity of views and understanding emerging from both institutional and non institutional arrangements.

The research aims to pinpoint problems at the level of policy and practice, examining disconnections between policy and practice and how these might be bridged. The rationale for extending the focus to both policy and practice is not only because these are closely related, but also because there is currently little insight in B&H and Bulgaria

into how disability is constructed, understood and addressed either in policy or practice. This becomes especially evident when governments, donors and international agencies place demands on practitioners to translate an inclusion agenda into practice.

The overall aim of the study is to understand the context and dynamics of policy and practice and to make recommendations that potentially can aid B&H and Bulgaria to develop a more inclusive/integrated society for children with disabilities and their families.

The main research question is: what are the opportunities for developing a more inclusive/integrated society for children with disabilities and their families in B&H and Bulgaria and what obstacles stand in the way of this?

The study produced the following key outcomes:

- A rich qualitative account of the situation for families with children with disabilities in Bosnia & Herzegovina and Bulgaria.
- A critique of current policies and disability politics as they relate to disability in Bosnia & Herzegovina and Bulgaria.
- Increased understanding of how accession to the European Union and the actions of international and supranational agencies influence the development of inclusion policies and practices in Bosnia & Herzegovina and Bulgaria.

- The identification of obstacles to developing more inclusive and integrated societies for children with disabilities and corresponding ways to overcome those obstacles in both countries.
- Identification of successful practices for developing the inclusion and integration of children with disabilities that may be applied in other Eastern European countries.

## WHY BOSNIA & HERZEGOVINA AND BULGARIA?

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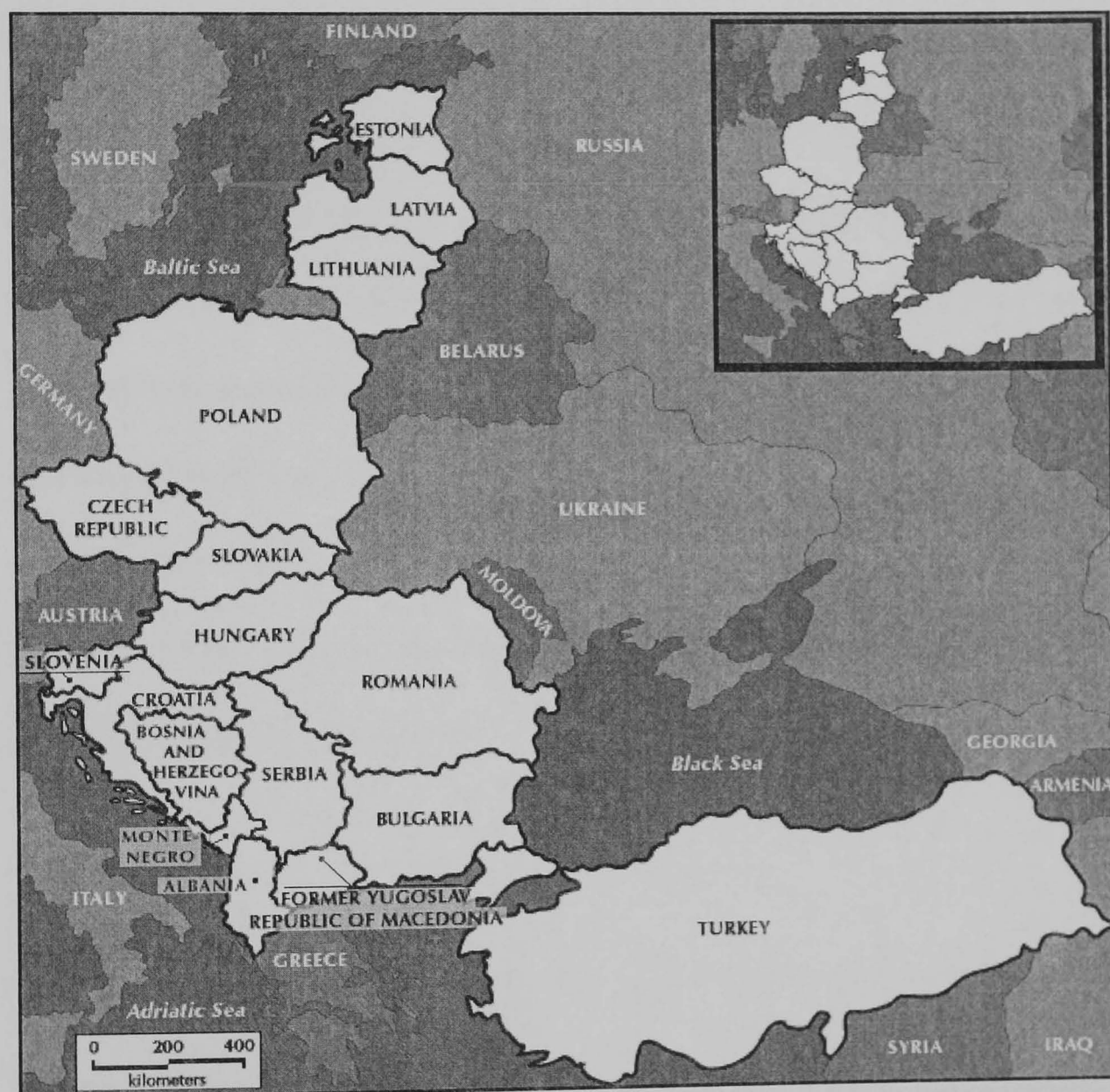
In its initial phases this study was informed by the UNICEF (2005) study 'Children and Disability in Transition in CEE/CIS and Baltic States'. This comprehensive study was used for identifying problems and issues faced by children with disabilities and their families in Eastern Europe. The UNICEF study examined the situation regionally employing statistical data to identify problems and qualitative research to illustrate their nature. The UNICEF research was conducted in 2003 and in recent years, given the rapid economic changes taking place and the ensuing diversity in policy and practice, the regional perspective is becoming increasingly difficult to capture. Therefore smaller scale cross country comparisons can provide valuable insights and examine inclusion through the experiences of children, parents and professionals. Recognising the need for an in-depth perspective, this study aims to develop, broaden and enhance the findings and conclusions from the UNICEF (2005) study by focusing on B&H and Bulgaria. In addition this study will document changes for children with disabilities made since 2003 when the original UNICEF study was conducted.

Bosnia & Herzegovina and Bulgaria were identified as suitable countries for this study on the basis of a number of similarities and differences between them. Similarities are a shared communist past, the prominence of the medical model in the treatment of disability and the influence of the Soviet school of thinking, for example in the practice of defectology. However the countries are also at different stages of EU accession, Bulgaria having already joined in 2007 while B&H is a potential candidate country which so far has concluded several pre-accession steps, though with actual accession uncertain. The process of joining the EU has considerable potential to influence the situation for children with disabilities because it requires reform of policies and bringing the care of vulnerable groups closer to EU standards. B&H and Bulgaria are selected for comparison also because they are in close geographic proximity, and broadly similar in size and economic and social indicators.

In terms of population, Bosnia and Herzegovina at 4.6 million people is smaller than Bulgaria which has 7.2 million. Bulgaria is a more urban country. B&H has a more favourable infant mortality rate and life expectancy, whilst Bulgaria has better economic indicators and employment rates. Both countries have high literacy rates at 96-98%. In B&H it is estimated that 24% of people live below the poverty line, compared to 14% in Bulgaria (Central Intelligence Agency, 2009). In 2008 the infant mortality rate for B&H was 6.9 and for Bulgaria 8.6. For illustration, figures for infant mortality rates for developed western economies such as Netherlands, Germany, Switzerland range between 1.8- 4.5 (United Nations Economic Commission for Europe, 2008). According to Human Development Report (UNDP, 2009) both B&H

and Bulgaria are classified as countries with a high human development index (HDI)<sup>1</sup>. B&H is ranked 76<sup>th</sup> and Bulgaria 61<sup>st</sup> out of 182 countries worldwide. Map 1 shows the geographic positions of B&H and Bulgaria.

Map 1. Geographic position of B&H and Bulgaria (The Regional and Environmental Centre for Central and Eastern Europe, 2009)



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<sup>1</sup> The human development index (HDI) looks beyond GDP to a broader definition of well-being providing a composite measure of three dimensions of human development: living a long and healthy life (measured by life expectancy), being educated (measured by adult literacy and gross enrolment in education) and having a decent standard of living (measured by purchasing power parity and income). It provides a broadened prism for viewing human progress and the complex relationship between income and well-being (UNDP, 2009).

The key difference between B&H and Bulgaria is in their practices of institutionalisation of disabled children. Placing children in an institution was historically quite common in Bulgaria, and much less so in B&H (UNICEF, 2005). Another important difference relates to the nature of the influence felt from their respective communist pasts (see chapter two). Bulgaria practised Soviet style communism, whilst B&H as a part of the former Yugoslavia experienced a more liberal style of communism - 'socialism with a human face'. This thesis shows that even under a shared communist ideology there existed nuanced but important differences between countries. These differences impacted differently on societal acceptance and practice with regard to children with disabilities in B&H and Bulgaria. Moreover twenty years after the transition from communism this thesis shows that these countries' political and social histories continue to affect children with disabilities and their families. This work also provides an opportunity to document changes that have been made and how these changes have impacted on disabled children and their families, since the extensive UNICEF (2005) study.

This study utilizes a qualitative methodology comprising focus groups and individual interviews. During the fieldwork the views of diverse participants were obtained in B&H and Bulgaria and the study reports and analyses the views of children with disabilities, their parents, professionals and policy makers. The fieldwork included insightful discussions with families and with children with intellectual disabilities who live in residential care concerning how they experience the consequences of policy and practice. These interviews tell a rich story and provide distinctive critiques of the current situation. This is an original contribution to knowledge in the context of B&H

and Bulgaria, with policy recommendations outlined in this study developed from both service users' and professionals' perspectives in both countries. Methodologically the study makes a contribution to knowledge by identifying and addressing issues related to conducting comparative qualitative work focused on disability. In the context of B&H and Bulgaria it has identified issues related to the understanding and translation of key terminology used in the field of disability. The study challenges assumptions about interviewing elites, working with translators and interviewing children who do not use speech to communicate.

#### NOTE ON TERMINOLOGY

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*Disabled children* or *children with disabilities* are expressions that carry different connotations and their use is frequently discussed in the literature. Influenced by the social model of disability, many disabled adults in the UK prefer 'disabled people' denoting the importance of a collective disability identity (Oliver & Barnes, 1998). On an international level 'people first' language is preferred, hence children with disabilities are viewed as a more appropriate order of words with the intention of signifying that disabled children are children first (UNICEF, 2005). 'People first' terminology is also used in the UN Convention on the Rights of Persons with Disabilities (UNCRPD). In this thesis the terms will be used interchangeably as both positions are seen as valid and both the social model of disability and human rights are used as conceptual frameworks. In addition as this research is conducted in Eastern Europe efforts were made not to assume universality of the social model, but to test the



concepts proposed by it. Therefore the tendency is to maintain an international dimension, through the use of literature produced by international organisations such as UNICEF, OECD, Save the Children, the World Bank, and the European Commission.

Throughout the study I avoided the term *children with special needs*, even though it is currently popular in B&H. This is because the term is frequently used in education. In B&H for example the usage extends to talented children, as well as children who live in poverty or children with behavioural problems. Acknowledging a lack of clarity with definitions and concepts, the OECD (2007, 2009) is engaged in active efforts to develop an internationally comparable framework, supporting countries of SEE, the Baltic Countries and Malta in developing classification systems based on the A, B, C model. This model is an internationally comparable approach according to which students are registered based on: a) disabilities, b) learning difficulties and c) disadvantage. Both B&H and Bulgaria are included in the OECD assessments and studies and both countries are moving towards this model. This new classification will help differentiate between disabled children and children who are still being classified as disabled because of disadvantage, such as Roma children (OECD, 2009).

*Roma children* are mentioned in this study as Roma issues have been conflated with disability, a fact which itself has implications for special schools and inclusion strategies and has contributed to a misinterpretation of official statistics. Due to material disadvantage and poor language skills, Roma children frequently find

themselves either excluded or placed in special schools upon being wrongly classified as having learning disabilities (Open Society Institute, 2007; UNICEF, 2007b; Becirevic, 2007). For example when the Bulgarian government reports on how many disabled children are included in mainstream schools, it is difficult to ascertain if those included children in the figures comprise Roma or only disabled children (Tsokova & Becirevic, 2009).

Whilst the issues of Roma need no explanation for Eastern Europeans I am aware that some clarification is needed for a UK and international audience. According to the Migration Policy Institute (2010), Roma also known as Romani or Gypsies are traditionally semi-nomadic people who came from Northern India to Europe some 1,000 years ago, where historically they have faced severe discrimination and persecution. Bulgaria has one of the largest populations of Roma, comprising about eight percent of the total population. A much smaller number of Roma are estimated to be in B&H, around two percent, a still significant number as they constitute the largest minority group in the country (Roma Education Fund, 2009). In the countries of Central and Eastern Europe (CEE) Roma children and their parents live in the most deprived areas, excluded from educational and employment opportunities and with poor access to services, often being victims of racially motivated crimes (European Roma Rights Centre, 2004).

The term *non-governmental organisation (NGO)* is frequently used in this study, but due to the diverse, heterogeneous and sometimes inconsistent interpretations of the term

clarification on its use is needed (Martens, 2002). It is beyond the scope of this thesis to examine the myriad legal and sociological definitions or for that matter the relationship between NGOs and civil society (these issues are in any case explored elsewhere e.g. Bebbington & Collision, 2006). Based on the definition offered by Teegan et al. (2004, p. 466) this thesis recognises organisations as NGOs if they are '*private, not-for-profit organisations that aim to serve particular societal interests by focusing advocacy and/or operational efforts on social, political and economic goals, including equity, education, health, environmental protection and human rights*'.

This study accessed views from people working in local NGOs which can be non-profit parents associations and/or locally registered citizens' initiatives. National NGOs which are organisations operating at the level of state, and whose activities are directed towards country wide rather than local issues are also included. Furthermore several international NGOs also took part in the study and these are larger non-profit organisations, currently operating in B&H and Bulgaria respectively, under the same philosophy, ideas and regulation as their umbrella organisation. Examples of such international NGOs would be Amnesty International, Save the Children, Caritas, and the Red Cross.

The term *international organisation* is used in this study and encompasses a diversity of supranational and regional aid organisations and agencies, financing institutions and donors (Stubbs, 2007). Supranational agencies are those that operate on a global basis,

such as the United Nations Children's Fund (UNICEF), United Nations Development Programme (UNDP) and international financial institutions, such as the World Bank (WB) and International Monetary Fund (IMF). Relevant regional organisations include the European Union and Council of Europe. There are also some national agencies which are particularly influential in the social policy field e.g. the United Kingdom's Department for International Development (DFID), the Swedish International Development Cooperation Agency (SIDA) and the United States Agency for International Development (USAID). In addition there are a number of foundations and trusts and programme oriented bodies - the prime example being the Open Society supported by George Soros.

## OUTLINE OF THE CHAPTERS

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Chapter one aims to identify the most useful theoretical frameworks and models to research and understand the social exclusion of disabled children and their families in B&H and Bulgaria. In this chapter the social exclusion of disabled children and families is approached through the main debates around social exclusion and the social model of disability. The thesis also benefits from insights provided by the 'new sociology of childhood' and debates on children's rights. The major premises of these models and theories will be outlined, but the principal challenge will be to identify to what extent these approaches can be used in understanding and overcoming exclusionary practices and cultures. These concepts are applied and debated in relation to disabled children and reveal an underexplored connectedness between exclusion and the social model of disability and the way the childhood of disabled children is understood.

Chapter two presents the historical and current context of B&H and Bulgaria in which exclusion/inclusion is investigated. The chapter examines the ways both communism and political and economic transition have shaped policies and practices for disabled children and their families. The chapter also looks into how EU accession, as the main political goal in these countries, is shaping disability policies. The chapter will identify and highlight the most important current issues disabled children and their families are faced with in these two countries.

Chapter three outlines the methodology used and gives an overview of methodological choices made during the conduct of the research and in the process of analysis. Apart from debating issues of using different qualitative methods the study was faced with challenges of researching hard to reach populations, residential institutions, and negotiating language and cultural barriers. The problems of doing qualitative work with the help of a translator, interviewing children who use little or no speech to communicate, as well as negotiating the positions of insider and outsider are reviewed in this chapter.

Chapters four, five, six and seven are data chapters where the voices of disabled children, their parents, practitioners and policy makers are used to identify and understand problems and subsequently to explore potential solutions. Chapter four provides insights into the way parents and children are affected by policies and practices. Chapter five is exclusively concerned with issues pertaining to residential homes for disabled children and residential special schools, places portrayed in the

literature as major obstacles to inclusion. Chapter six considers the way professional practices and services act as facilitators or obstacles to inclusion. Chapter seven highlights the tensions and contradictions introduced by the work of international organisations and the actions of a growing civil society. This chapter also discusses dilemmas when translating international disability agenda into the contexts of B&H and Bulgaria.

Chapter eight, the concluding chapter debates the major findings from the study. This final chapter discusses how the study and the thesis fulfilled the research objectives, question, aims and outcomes. Additionally the chapter discusses the application and usefulness of the concepts of children's rights, social exclusion and the social model of disability in researching exclusion and advancing an agenda of inclusion for disabled children and their families in B&H and Bulgaria. This chapter also suggests ways forward and offers policy and practice recommendations for the future.

# CHAPTER 1

## OVERCOMING 'CONCEPTUAL HOMELESSNESS' - SOCIAL EXCLUSION OF DISABLED CHILDREN

---

The concept of social exclusion is central to this study because disabled children and their families are exposed to high levels of social exclusion, poverty and denial of rights. This phenomenon is not confined to Bosnia and Herzegovina and Bulgaria, but is a significant problem recognised on an international level (Middleton, 1999; Dowling & Dolan, 2001; UNICEF, 2005; Clarke, 2006; Sloper & Beresford, 2006; European Commission, 2009). This chapter will first examine literature which highlights the characteristics of the social exclusion of disabled children and their families. The second part of this chapter will examine the application of the social model in researching the exclusion of disabled children and their families.

The thesis is also informed by the children's rights agenda and the 'new sociology of childhood' (Jenks, 1996; James and Prout, 1997; Mayall, 2000). In the third part of this chapter the relationship between these two approaches is explored with the aim of explaining why the rights of disabled children are advancing slowly. Qvortrup's (2007, p. 395) 'conceptual homelessness' phrase is borrowed to describe the lack of a unified framework, concept and theory in examining the exclusion of disabled children. The concluding part of this chapter seeks to demonstrate that this conceptual homelessness can be overcome by utilising connectedness between social exclusion, the social model of disability, children's rights and the 'new sociology of childhood'.

## 1.1 APPLYING THE SOCIAL EXCLUSION CONCEPT TO DISABLED CHILDREN AND THEIR FAMILIES

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The concept of social exclusion was first used by René Lenoir in France in the 1970s to discuss poverty and disadvantage and exclusion from labour markets and welfare systems (Popay et al., 2006). The concept has developed further, as is evident from a large body of academic literature and policy discourse and it is now frequently used in relation to disabled children (Morris, 2001; Sharma, 2002; Clarke, 2006; UNICEF 2005, 2007; Morris et al., 2009). Social exclusion is a concept developed from two leading European social policy traditions: social democracy, concerned with inequality and equal opportunities, and social catholic concern for social ties in the community and within the family (Coates et al., 2001, p.9). In the early 1990s the concept of social exclusion came onto the European policy agenda, replacing poverty, as key terminology. This can be seen in the work, reports and conferences organised by international organisations such as UNICEF, OECD, European Commission (Kamerman, 2001).

In Britain the social exclusion concept emerged on the government's policy agenda with the Labour Government in 1997, which set up an interdepartmental Social Exclusion Unit (Burchardt, et al., 1999). Burchardt et al. (1999) developed a working definition of social exclusion for the purpose of analysing social policy problems in Britain. They argued that the individual is socially excluded if he or she lives in a society, but for reasons beyond individual control does not participate in the normal



activities of citizens in that society, even though he or she would like to participate.

The socially excluded are not people who withdraw themselves from participation, but those who cannot participate because of discrimination, lack of opportunities and hostility. Normal activities for Burchardt et al. (1999, p. 231) are the following four most important areas of participation: *'to have a reasonable living standard, to be engaged in activities which are valued by others, to have some decision making power, and to be able to draw support from immediate family, friends and wider community'*.

In spite of its growing use and popularity in policy discourse, the concept of social exclusion has been criticised for diverting attention from poverty and income inequalities (Levitas, 2005). In addition it has been criticised for being without a clear mechanism for monitoring (Johoel-Gijsbers & Vrooman, 2007). In analysing and critiquing the concept Levitas (2005) identifies different discourses on social exclusion: a redistributive discourse concerned with the need to overcome poverty and inequality; a moralist underclass discourse that puts blame on the morals and behaviour of those who are excluded and a social inclusion discourse which argues that work is the main component of social integration. Along similar lines Moore et al. (2008) link perspectives from critical disability studies, child rights and social exclusion, dividing discourse on exclusion into two types. On one side there is a moral underclass discourse that relates social exclusion to a decline in moral standards and children's and parents' poor educational achievement (especially that of single and teenage mothers) and rejects discrimination as the cause of exclusion. They contrast this with the social integration discourse that seeks causes for exclusion not by blaming

individuals but blaming their social circumstances and their lack of access to employment and education.

In spite of the difficulties which surround the concept currently, there is a broad agreement that exclusion is a wider, multi-dimensional and potentially less stigmatising concept than poverty (Levitas, 2005). This multidimensionality means that social exclusion is '*constituted by a layering of conditions one upon another generated by an interaction of economic, social and political circumstances*' (Daly, 2006, p. 4). The complexity of social exclusion is addressed by Saraceno (2001, p. 4) who argues that the concept is linked to two different genealogies; on the one hand poverty and material deprivation, and on the other hand social disintegration, marginality, un-belonging and up-rootedness. So, according to Saraceno social exclusion is conceptualised in this twofold dimension, which deals with social conditions (by which individuals or groups are excluded from resources and social rights), and points to detachment from networks, and a lack of identification within a community. These two aspects are important to bear in mind when analysing the social exclusion of disabled children, especially since the income of parents is not always taken into consideration when addressing exclusion. In line with this Dowling (1999, p. 246) argues that '*poverty is the great excluder for many people because poverty is concerned not only with lack of income, but with the lack of choice and opportunities that wealthier people, however otherwise excluded, still enjoy*'.

The way the European Union (EU) approaches exclusion is important for this study, because the EU directives and policy objectives are being interpreted by current member states (Bulgaria) and potential member states (B&H). However the EU exclusion agenda has been criticised because of different interpretations in individual member states, and because of prioritising employment and market deprivation over social, political or cultural dimensions (Atkinson & Davoudi, 2000; Silver & Miller, 2002). Nevertheless the social exclusion agenda has been continuously strengthened at the level of EU by giving more attention to social policies and developing monitoring mechanisms for exclusion/inclusion. This is especially evident in the Laeken indicators adopted in 2001 for use by Member States in reporting on social inclusion (Atkinson et al., 2005). Furthermore the European Commission (2010, p. 5) recognises that gender differences and inequities are a key feature of social exclusion and poverty and incorporates a gender based analysis in understanding the extent of social exclusion among disadvantaged groups, including disabled people.

More attention to exclusion is also evident in action '2010 European Year for Combating Poverty and Social Exclusion' (European Communities, 2010). The idea is to unite the member states to raise awareness about people who live in poverty and social exclusion; to engage with these issues and challenge stereotypes about poverty; to increase solidarity and ensure everyone can play an active role in society. This indicates that criticisms that social exclusion strategies disregard poverty (Levitas, 2005; Béland, 2007) are being taken seriously. The member states will support activities, such as campaigns, workshops, films and magazines to increase understanding of how poverty and social exclusion affect communities. For those

directly affected, they are intended to increase awareness of their rights (European Communities, 2010). As a member of the EU Bulgaria is participating in this program and their plan of action reveals a strong focus on families, on disabled people and on children living in institutions (Republic of Bulgaria, 2010).

Furthermore the need to examine how the actions of the EU influence social exclusion agendas in particular countries is in line with the work of Popay et al. (2006) who argue for a relational perspective on social exclusion that goes beyond the national perspective. This perspective looks at the effect of a wide range of agents such as globalisation, multi-nationals and international agencies such as the World Bank and IMF, as well as national institutions. It allows for analysis of exclusionary processes on micro, meso and macro levels, from families through to international agencies. It examines processes that exclude and deprive whole nations, or groups, on the basis of their social characteristics because of exclusionary international politics. This perspective is taken into account in this research and the influence of international agents in shaping social and inclusion policies in B&H and Bulgaria is considered in chapters two and seven. Since this study is about social exclusion and disabled children, the next section will examine social exclusion in relation to this group specifically.

#### 1.1.1.1 UNDERSTANDING SOCIAL EXCLUSION AND INCLUSION OF DISABLED CHILDREN

In analysing the exclusion of disabled children in the UK Clarke (2006) confirms the previously stated argument that socio-economic disadvantage, though not the only

one, is a very important cause of social exclusion. Others tend to stress different factors of exclusion, and Kamerman (2001, p. 13) argues that the concept of social exclusion is important because it goes beyond income poverty and thus is better equipped to provide insights and solutions to a wider range of problems and disadvantages.

Kamerman supports the argument, by taking an example from France, a country with widely available and publicly funded early education programmes, as well as strong child and family policies. These measures lessen the impact of income poverty and support the social inclusion of children from early on, meaning that poverty alone does not have to cause social exclusion as long as education and community resources are available. In countries where these programmes are not available the effects of parental unemployment or low income are more likely to produce more adverse effects and probably pull children into social exclusion, due to parents being unable to afford to participate.

Although different dimensions of social inclusion need to be acknowledged, it is important not to underplay the economic and social disadvantages of disabled children and their families and this is documented in many studies. For example Sloper and Beresford (2006) point out the grave financial situation that many families with disabled children live in with 55% living in poverty. A disabled child brings additional costs to the family and due to a number of constraints, such as child care needs and often frequent medical appointments, paid work for the parents may not be a solution. For 90% of these parents, state benefits are the only, but far from sufficient, source of income (Sloper & Beresford, 2006). Furthermore, Preston (2006) reports that benefits do make a difference to families, but they are not always easy to access, and fluctuations

in or removal of benefits contribute to family stress. Due to care demands, unsuitable housing and unmet needs, families with disabled children have higher levels of stress and lower levels of wellbeing (Sloper & Beresford, 2006; Clavering, 2007). The exclusion of disabled children can be related to Amartya Sen's popular concept of capability deprivation (2000). Sen argues that poverty does not only mean low income, but capability deprivation as well. For example, being excluded from social relations can lead to other deprivations, whilst being unemployed can cause undernourishment or homelessness. In this respect social exclusion is a part of capability deprivation as well as instrumental in diverse capability failures (Sen, 2000, p. 5).

Even though exclusion, disability and poverty are interrelated (Oliver, 2004) it needs to be acknowledged that disabled children are frequently excluded even without the poverty dimension. For example, if a child lives in a disability unfriendly and inaccessible town or village, with poor or no education and lack of opportunity to build friendships, it is likely that the child will be excluded. Exclusion from mainstream schools or living in residential care away from family, or not having friends are aspects of exclusion often experienced specifically by disabled children (Morris, 2001; Sharma, 2002; Priestley, 2003). In addition, exclusion from mainstream community services is another factor compounding the isolation of disabled children and their families (Morris & Barnes, 2008). Young disabled people summarise their experiences of exclusion as: not being consulted or listened to; having no friends or finding it difficult to make friends; and being made to feel a burden with no contribution to make (Morris, 2001, pp. 163-164).

Morris, et al. (2009) argue that the potential of the concept of social exclusion is in understanding the situation of those whose exclusion is not necessarily related to poverty, such as disabled children. In addition, instead of imposing normative expectations on families the concept has the potential to examine the roles of those who are doing the excluding. They argue that different dimensions of social exclusion interact in different ways for different social groups and the list below, adopted from Morris, et al. (2009) explores these dimensions in relation to disabled children:

- Material deprivation is particularly significant for families with disabled children, due to the cost of raising them, and to the time consuming and emotionally draining negotiation of benefit systems. This is coupled with housing which is frequently not appropriate for disabled children's needs.
- Spatial exclusion is another dimension that affects disabled children. This dimension is related to physical barriers that restrict their movement and mobility. In addition disabled children are often segregated in special schools, preventing them from taking part in inclusive leisure activities because of the travel time to school, friendship networks linked to schools and lack of knowledge about community-based opportunities.
- Access to goods and services presents a further dimension of exclusion, due to restricted access and the lack of integrated services. The restrictions are caused by a lack of coordination between services; the lack of training for youth and play workers in how to support disabled children, as well as the overall experience of attitudinal and physical barriers.

- Self determination is a dimension where children in general, but disabled children in particular tend to be excluded, because they are regarded as incapable of making decisions about their life choices.
- Participation is a dimension where disabled children tend to be excluded frequently and this dimension will be especially addressed later in this chapter.

Barnes and Morris (2008) reviewed strategies for the prevention of exclusion used in the National Evaluation of the Children's Fund and identified two different types of strategies. One strategy focuses on children's and families' well being by developing children's life skills and independence and improving family relationships. The second strategy aims to increase children's participation in services; increase their confidence; enable children to gain qualifications and encourage some children who had been users of services to become involved in running them. Evans and Plumridge (2007) argue that the way services respond to exclusion is connected to their concepts of inclusion. They documented how many service providers see specialist provision as inclusive because it provides disabled children with opportunities similar to those offered to non-disabled children. These types of provisions are then seen as facilitating children's networking with their peers in special school and helping children not to feel different. Other service providers interpret inclusion as providing integrated activities for disabled and non-disabled children, with the idea of enabling disabled children to build social networks with their non-disabled and disabled peers and promote their social inclusion in their community. This strategy did not necessarily result in disabled and non-disabled children playing together (Evans & Plumridge, 2007).



Building resilience is also seen as way to guard against social exclusion. Burchardt and Huerta (2008) argue that even though both resilience and social exclusion are slippery concepts, there is much to be learned, in terms of policy implications, from considering the two together. Resilience can be derived from individual factors, family factors, and also wider social networks. According to Edwards (2007) resilience is due to interactions, rather than being a characteristic of individual psychology. Even though networks and social capital are not recognised much in policy discourse there is a potential for resilience and social capital being increasingly explored as a strategy to fight social exclusion (Barnes & Morris, 2007). For example Evans and Plumridge argue that disabled children need to be supported to develop networks amongst both disabled and non-disabled children whilst practices need to be focused on children within families rather than as individuals. The relevance of social capital, networks and resilience is explored in chapter four of this thesis in relation to disabled children and parents in B&H and Bulgaria.

As the title of this thesis suggests I will be examining whether policies and practices in B&H and Bulgaria are more about the illusion of inclusion than actual inclusion.

Literature on the concept of social inclusion describes it in positive terms as the policies and strategies used in overcoming social exclusion (Davis & Hill, 2006). It is, as such, an affirmative action, in opposition to social exclusion. In this thesis I am arguing that designing and implementing inclusion strategies requires recognition of exclusionary forces, though there is also a need to understand exactly what social inclusion is.

Significant attention has been devoted to defining educational inclusion and there is general agreement that inclusive education is a process whereby a school attempts to

respond to pupils' diversity by firstly re-examining and adjusting its curricular organisation and provision, and secondly by allocating appropriate resources to enhance equality of opportunity (Sebba & Ainscow, 1996; Booth, et al., 2000). Inclusive education means learning together and enabling all students to participate fully in life and work within a mainstream setting, whatever their needs happen to be (The Centre for Studies on Inclusive Education, 2002). Inclusion entails re-examining and restructuring cultures, policies and practices in schools so that they respond to the diversity of students in the locality. While the primary focus in this work is not on education, inclusion in education is an important aspect of inclusion in society.

Due to the complexity of the social inclusion concept I have approached it analytically and critically rather than confining it to one single definition. This critique of social inclusion is based on reviewing a number of sources that deal with the exclusion and inclusion of disabled children (e.g. Middleton, 1999; Morris, 2001; ECF, 2003; Clarke, 2006; UNICEF, 2007; Morris et al., 2009). It has been suggested that inclusion can be considered to be about '*identifying, understanding and breaking down the barriers to participation and belonging*' (ECF, 2003, p.1). This definition however is rather broad for a project that takes an in-depth approach when examining the exclusion and inclusion of disabled children and their families. Inclusion incorporates many different issues: respect for children's rights, equal opportunities, equal access to education, having an appropriate standard of living, participating in social life, enjoying respect and a sense of belonging.

In addition there is agreement that inclusion is a process, not a project or a condition. Societies strive for this process through a series of deliberate actions: reducing barriers to participation, reducing discrimination, increasing equality, respecting human rights, learning to value members and improving services. For disabled children, this means living with their families instead of in segregated special educational and residential schools, it means being safe, accessing education in their locality, having unrestricted access to transport and community facilities, being able to access leisure facilities, exercising choice, having opportunities, being valued, accepted, and listened to respectfully. Furthermore it entails disabled children having positive social relationships, being members of the community, having a sense of belonging and achievement, all of which provides a setting where people can reach their full potential. This must be the case for all children, not just disabled children; an environment '*where diversity is a norm, rather than the exception*' (UNICEF, 2007, p.1).

Overall, educational and social inclusion discourse is very much about being part of mainstream, non-disabled society. However, this thesis shows that inclusion is more complex than that, as being with non-disabled children and attending mainstream schools does not necessarily mean that children will participate and become included or happy with this arrangement. There are examples of disabled children developing a sense of belonging and meaningful friendships in special schools or building a positive disability identity in socializing with other disabled children (French, 2004). This study accessed the views of children living in different circumstances, some with their families, some in segregated care homes and schools, with little prospects of change.

So, in efforts towards inclusion, do we consider the diversity of circumstances disabled

children live in a certain point in time, or do we reject outright arrangements that do not fit with popular inclusion discourse? Reflecting on examples from children and parents (see chapters four and five) the thesis will later tackle this question. Since the social model of disability features as an important component of combating exclusion and achieving inclusion (Oliver & Barnes, 1998) the next section will focus on this.

## 1.2 THE SOCIAL MODEL OF DISABILITY AND DISABLED CHILDREN

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The social model of disability came as a response to the individual model that was particularly used in the medical and therapeutic literature (Priestley, 2003). This model, frequently referred to as the medical model, was located in the academic disciplines of medicine, psychology and special education and it propagated rehabilitation, cures and the domination of medical professionals over the lives of disabled children and adults (Barnes, 2004; Hughes, 2004). The distinction between the individual and the social model of disability was expressed academically in the early 80s by the sociologist Mike Oliver, but the original impetus came from the disabled people's movement in the UK (Oliver, 1983; Barnes, 1997; Finkelstein, 2001; Priestley, 2004; Thomas, 2004; Shakespeare, 2006). The Union of the Physically Impaired Against Segregation (UPIAS) developed this popular definition of disability that signified a new era in studying disability:

*The disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities' (quoted in Bernal, 2006, UPIAS 176: 3-4).*

Oliver (2004, p. 7) argues that the social model of disability '*turned our understanding of disability completely on its head*' by arguing that the main problems experienced by disabled people are not impairments but the way society responds to impairment.

The social model of disability is different to normalisation and to social role valorisation, the concepts very influential in shaping policy and practice for people with intellectual disabilities. Normalisation originated in Scandinavia in 1960s and it was based on the key idea that people with intellectual disabilities should be supported to lead lives as close to the norms and patterns of mainstream society as possible (Yates, Dyson & Hiles, 2008). Normalisation was reconceptualised and elaborated by Wolfensberger (1972) who renamed it Social Role Valorisation (SRV) and argued that people's behaviours, appearances, experiences status and reputation need to be culturally as normative as possible so that they would not be socially devalued. This included challenging the association with other devalued individuals (in Walmsley, 2006, p. 42). Normalisation and SRV have been criticised, especially by the proponents of the social model of disability and feminists, for promoting conformity and normality, suppressing diversity and difference and for placing an emphasis on changing the individual. Still normalisation made some significant beneficial impacts on policy and practices, such as the development of community-based services and contributing to a reduction in segregated education and housing (Walmsley, 2006).

According to Barnes (1997, p. 5) socio/political theories of disability emerged from two separate but connected strands. The first is rooted in American functionalism and

deviance theory, and explains the 'social construction' of disability as an outcome of the evolution of contemporary society. The second, British strand, is based in the materialist analysis of history associated with Marx, with the main argument being that disability and dependency are the 'social creations' of industrial capitalism. The causal mechanisms involved were located in the capitalist system of production and exchange and in Marxist historical materialism (Thomas, 2004). The social model of disability took an opposing approach to the medical model by identifying problems, deficiencies and inadequacy in society. The social model is a materialist approach, focused on societal structures, rejecting methodological individualism and psychologically inclined explanations of disablement (Shakespeare, 2006).

One of the main criticisms of the social model is its refusal to deal with diversity of experience and conceptions of gender, race and ethnicity in relation to disability (Watson, 2004; Shakespeare, 2006). The radical proponents of the social model, such as Finkelstein (2001) strongly criticised those who included impairments in their analysis, as impairment was seen as a personal and disability as a social issue (Hughes, 2004). In spite of criticism, feminist disability scholars claimed that the personal is political and went on to incorporate the experience of impairment in their research (see Morris, 1991-Pride against Prejudice; Thomas 2001). Oliver (2004) responds to these criticisms by arguing that even though the social model has not adequately responded to diversity so far, it does not mean it is unable to do so.

In spite of its popularity and widespread use in challenging oppressions and exposing injustices in society, Finkelstein (2001) and Oliver (1996, 2004), who were instrumental in developing it, argue that the social model is not a theory of disability, but a model; a practical tool for achieving greater justice for disabled people. Finkelstein (2001) argues that, as a good model, it enables us to see something from different viewpoints, thus providing insights which we otherwise might not develop. In that respect according to Finkelstein the social model of disability is a stage in gaining insight into a complex situation, but a theory is a later stage in the process that provides an explanation of this situation. As this thesis seeks to identify barriers to inclusion of disabled children, the social model is seen as an appropriate tool (Shakespeare & Watson, 2002). The thesis is also concerned with rights of disabled children and the social model is increasingly being used in supporting and taking forward the human rights agenda, as evident in the UN Convention on the Rights of Persons with Disabilities (2006).

#### 1.2.1 THE SOCIAL MODEL OF DISABILITY AND EXCLUSION OF DISABLED CHILDREN

Even though knowledge about using the social model of disability to examine the exclusion of disabled children is underdeveloped, important contributions are growing continuously (Morris, 1998, 2001; Middleton, 1999; Davis & Watson, 2000; Sharma, 2002; Priestley, 2004; Davis & Hogan, 2004; Clarke, 2006). The social model is very powerful in drawing attention to problems within society, so that society is made responsible for preventing disabled children from achieving their full potential. Examining experiences of disabled children Middleton (1999) argues that the social model of disability can help disabled children's inclusion and the fulfilment of wishes, hopes and dreams by challenging social, attitudinal and environmental barriers to

these aspirations. It also focuses attention on looking for ways to dismantle barriers, instead of focusing on the children as the problem.

Dowling and Dolan (2001) use the social model of disability to illustrate the ways in which social organisations disable not just the family member who has an impairment, but the whole family unit. They argue that families with disabled children experience a range of inequalities that other families do not suffer. Going beyond the effects of poverty they argue that families with disabled children experience unequal opportunities and outcomes in work, leisure, finance and quality of family life. This perspective of applying the social model to the family unit is underexplored, but chapter four demonstrates its relevance. However the social model of disability cannot be applied to all families in advancing social inclusion; its application is not straightforward for broken or dysfunctional families, families where abuse occurs, or situations when a disabled child is institutionalised or fostered.

Inclusive education is an area where the social model of disability found its application in relation to disabled children early on. The philosophy of inclusive education moved away from the idea of mainstreaming - placing a disabled child in and adjusting them to a mainstream school. Instead, inclusive education advocates changes on the level of schools, removal of physical and attitudinal barriers to include disabled children and other children who do not fit into the category of average pupils (Booth & Ainscow, 1998; Booth, et al., 2000; Allan, 2006). The disability rights movement and the social model of disability paved the way for policy changes on inclusive education, which has



managed to change the paradigm of disability from a medical welfare model to human rights model in the last twenty years (Rioux, 2001).

The experiences of children with disabilities can be explored further within the social model framework if they are supported to participate and take part on their own terms (Morris, 2001; Priestley, 2004; Davis & Hogan, 2004). Connors and Stalker (2007) argue that introducing children to alternative views about their disability, such as the social model, especially when young people are going through stages of identity formation, can serve as a foundation for self confidence and self worth in years to come. Those who use the social model of disability as their framework, in relation to disabled children, tend to adopt a perspective of incorporating children's experiences in examining exclusionary barriers, even though this is seen as drifting away from the original social model, as discussed before (Morris, 1998; Priestley 2004; Connors & Stalker, 2007). Westcott and Cross (1996) argue that the social model of disability is important in empowering disabled children by helping them understand that what is to blame does not reside within them.

Even when not explicitly used, it is evident in the literature that the social model of disability informs current research about disabled children. There is a notable tendency in the literature, although not so much in the media to move away from 'personal tragedy' discourse and the suffering of families towards a narrative around disadvantage, poverty, barriers to schooling, employability of parents and lack of access to services (see Sharma, 2002; Clark, 2006; Bernal, 2006; Clavering et al., 2006). In

addition there is an increasing inclination to use a socio-cultural construction in understanding disability alongside the social model of disability. For example Morris (1991) argues that disability frightens non-disabled people because of the projection that same could happen to them. This fear can make them separate disability from common human experience in order to avoid having to think about it.

Shakespeare (1997) takes these arguments further and provides analyses of religious, literary, and media representation of disability in which disabled people and children are changelings or the product of evil, or punishments, who become villains and/or objects of pity. Analysis of these representations and cultural stereotyping helps in understanding prejudice towards disability. It shows the tendency to increase 'otherness' and objectify disabled people in charity adverts by provoking the psychological reaction of pity. Shakespeare (1997) –like Morris - argues that the problem is that disabled people remind non-disabled people of their own vulnerability. In addition Shakespeare (1997, p.229) argues that the social model of disability needs to be reconceptualised to include the understanding that people with impairment are disabled, not just by material discrimination, but also by interpersonal, cultural and social prejudice. The analysis of cultural stereotypes and prejudice contributes to understanding the exclusion of disabled children and the experiences of prejudice will be discussed later in chapters four and five.

In spite of criticisms addressed in this section the social model of disability is seen as a powerful tool in addressing the exclusion of disabled children. This thesis makes a

contribution by exploring use of this model in B&H and Bulgaria and this is especially addressed in chapter seven. However, as previously argued the social model of disability does not have the explanatory function of theory and as such can provide insights but cannot fully explain the complex phenomenon of social exclusion of disabled children and their families (Finkelstein, 2001; Oliver, 2004). According to Thomas (2004) those who work within the framework of the social model of disability rely on other sources in their search for explanations as to why social exclusion on the grounds of impairment persists. In searching for explanations this research draws on insights provided by the sociological theory of childhood.

### 1.3. DISABLED CHILDHOOD WITH(OUT) RIGHTS

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This section explores the relationship between children's rights and the way childhood is socio-politically constructed. This approach of studying a child in a societal context, is seen as appropriate for this thesis as the phenomenon of exclusion is essentially a social one, as argued in previous sections of this chapter. Traditional child development theories (for example those of Piaget (1952) and Erikson (1950)) established an approach that treats children as natural and universal, ignoring children's social and cultural particularities, as well as children's views (Jenks, 1996; Hill & Tisdall, 1997). This generated an understanding that children are beings in making, progressing through defined developmental and maturation stages (Kehily, 2004; Lansdown, 2005).

Furthermore, until the 'new sociology of childhood' emerged, children's issues in sociology were ignored almost completely apart from those dealing with education, family and socialisation, whilst children's worlds, contribution to society, wishes and perspectives were of limited interest (Bühler-Niederberger, 2010, p.156). The 'new sociology of childhood' changed this and turned the focus onto examining children's lives from their own perspectives, and considering children themselves as active social agents in their own right (Kehily, 2004). This framework is based on a constructivist and interpretive approach and it sees children's experiences as resulting from interaction with environments and people around them, as opposed to being biologically predetermined (Cocks, 2009). Importantly this approach sees children and childhood as a permanent structure of society, a state of being instead of one of becoming (Qvortrup, 2007).

The most influential in our understanding of childhood is a famous work by historian Philippe Aries (1962), who argued that the childhood is a very new concept that did not exist at all in the medieval period. In the medieval world there was no concept of childhood and a young person of seven was already seen as an adult. Building his thesis on analysis of artwork, Aries argues that, in paintings, children appeared without the characteristics of childhood, but as adults on a smaller scale. Childhood only started to be recognised as different from adulthood in the 18th century. This supports ideas by the 'new sociology of childhood', emphasising that our views towards children and childhood are constructed within historical, social and political changes (James & Prout, 1997; Mayall, 2000; Kehily, 2004).

In addition anthropological studies showed that understanding of childhood is different in different cultures (Montgomery, 2009), which further supports a social construction perspective of childhood. Recognizing ways in which childhood is constructed is important for this thesis, because understandings of childhood shape child rearing policies and practices, thus influencing the lives of disabled children (Hill & Tisdall, 1997). Roche and Tucker (2003) support this by arguing that debates and policies about exclusion are embedded in socio-political concerns and the tendency to control and steer young people. The 'new sociology of childhood' claims that childhood, as well as our views of children vary; there is not one single natural childhood that has to follow a certain path and that children's experiences need to be examined in order to understand their lives. For those reasons this approach is increasingly being recognised as a suitable framework for research with disabled children (Middleton, 1999; Connors & Stalker, 2003; Priestley, 2003; Kelly, 2005).

In addition Reynaert et al. (2009) show that studies of childhood and children's rights are frequently connected in academic literature. They argue that since the adoption of the UNCRC there has been a preoccupation with ideas from the 'new sociology of childhood', highlighting the image of the competent child, which resonates with a rights perspective. On the other hand, the view of the child as a 'work in progress' represents a protectionist, welfare perspective on childhood. It is also recognised that the children's rights movement is supported by the 'new sociology of childhood' and vice versa (King, 2007). The 'new sociology of childhood' supports children's rights, which on its own, may appear as a set of prescribed rules, or rhetoric or a tool communicating western ideas about children (Burr, 2002). Franklin (2002) argues that a

sociological paradigm on children and childhood, which views children as social rather than biological constructs, supports the progress of children's rights. Mayall (2000, p. 243) also claims that childhood and children's rights are connected: *'It is through working towards better understanding of the social condition of childhood that we can provide a firm basis for working towards implementation of their rights'*.

However, it should not be forgotten that whether children should or should not have rights is subject to intense philosophical debates and it is again to do with how we conceptualise children, childhood and rights. Archard (2006) summarises that these views range from thinking of children as unequipped to have rights, especially young children, to liberationist arguments that children should have as many rights as adults. In between are those who think that children should have some but not all the rights of adults, and may have some rights afforded to them because of the special status of childhood. Archard considers that philosophical arguments about rights hinge on contentions that rights are linked to capacity to exercise choice, so that children who do not have that capacity, in theory should not have rights. Another tension arises from the concept that rights concern doing, being or possessing and so only those rights can be possessed whose content can be appropriately attributed to their owners. From that perspective, a right to free speech cannot properly be possessed by a person incapable of speech (Archard, 2006). In spite of philosophical debates and tensions around children's rights the UNCRC recognizes children as having agency, as well as rights to protection.

### 1.3.1 THE UNITED NATIONS CONVENTION ON THE RIGHTS OF THE CHILD

Alston et al. (2005) trace the development of children's rights through history showing that the need to recognize children's rights grew steadily through the twentieth century. After the relative invisibility of children's issues on international levels in the nineteenth century, the catalyst for change was reaction to the plight of exploited working children; horror at the sexual exploitation of children, and the suffering of children in times of war. The adoption of the 1959 UN Declaration on the Rights of the Child was groundbreaking, as it gave recognition to children's need for love and affection and protection; but it did not recognize civil and political rights, and it was not about empowering children, but protecting them. The present 1989 UN Convention on the Rights of the Child (UNCRC) came at a time of strong consciousness of children's rights at the international level and a specific socio-political context. The period of 1989-2000 was marked by the fall of the Berlin Wall and great enthusiasm for human rights, and the idea that human rights would be one of the foundation stones of a new world order, including numerous international initiatives for human rights (Alston et al., 2005). This historical perspective further strengthens the idea that our changing views of children and childhood, and our subsequent approach towards children cannot be divorced from the socio-political context.

Currently on a universal international level there is an agreement that children have rights. This was confirmed by the UNCRC which was adopted unanimously by the General Assembly on 20 November 1989. To date, the UNCRC has been ratified by 191 States, but not Somalia or the United States. The Convention is of paramount importance because it is the first binding instrument in international law to deal with

the rights of children. It is based on four main principles: non-discrimination, best interests of the child, the right to life and development, and participation. The crucial element of human rights is the norm that every human being has a value and significance, and that is not only because they are economically or otherwise useful but because of their inherent self-worth (Quinn & Degener, 2002). The articles of the Convention cover social, economic and cultural rights, as well as civil and political rights. The Convention asserts that every child has the right to health care, education and social security and protection from violence. Children's civil and political rights include having his/her opinion taken into account, the right to freedom of speech and association, the right of access to appropriate information and the right to identity.

A major issue with the Convention is a tension between the protectionist values it promotes, and independence. Archard (2004) argues that this tension is especially evident between article 3 and article 12, where the former requires those dealing with children to make their best interest the priority, whilst article 12 gives children the right to express their views on matters concerning them and sees children as entitled, albeit to varying degrees to try to govern their own lives. This tension is very important for disabled children. Their lives are frequently dominated by professionals and decisions made by professionals, who act as though they know what is in the best interest of that child. In spite of tensions there is a recognition that the UNCRC has the potential to improve the lives of children if it is taken as an approach that informs policy and legislation (Franklin, 2002). This is also argued by Pesikan (2003) who nevertheless reminds us that human rights only make sense if they are not only theoretical but also have practical applications, are embedded into national legislation



and practices and become a way of life. The discourse of the Convention implies that rights are laws immediately expected to be observed, but as it will be explored throughout the thesis this is not always the case. Instead “right” is more of a starting point that sometimes takes a long time to translate in practice, especially when it comes to disabled children.

### 1.3.2 CHILDREN’S RIGHTS- ‘A DISTANT AMBITION FOR DISABLED CHILDREN’

Even though UNCRC addresses disability specifically only in article 23, it must not be forgotten that every article extends to disabled children, as the Convention prohibits discrimination on the grounds of disability (see article 2). Kilkelly (2002) says that the provision in the Convention that stipulates a child’s right to live with family and not to be separated from family against their will (articles 7 and 9), or to keep contacts with his/her family is very important for disabled children. This is because disabled children are more likely to be separated from parents and placed in institutional care. Since disabled children are vulnerable to abuse in residential settings, article 19 is important because it stipulates that children should be protected from abuse whether the abuse or violence occurs in the home, at school, in a residential setting or in custody. The right to education (articles 28 and 29) of all children is of great importance to disabled children, since this right is also frequently denied. The respect for the child’s right to education is a prerequisite for ensuring respect for all the child’s rights under the Convention as a whole, as set out in General Comment No. 1.

In spite of the above proclamations, the rights of disabled children are frequently violated and denied (Morris, 2001; UNICEF, 2005, 2007). Middleton (1999) argues that some of this is because of the tendency to see impairment before seeing the child. Even though the 'children first' position is criticized by the disability movement, if we forget that disabled children are children first, the rights that apply to other children can be overlooked for disabled children. *"Choices and rights" is the theme song of the disability movement, but can seem like a distant ambition for disabled children whose experience is often of not being in control* (Middleton, 1999, p.18). Middleton says that crusades against impairment through medical interventions, daunting social experiences, parental control, and negative views towards disability, abuse and segregated education are only some aspects of disabled children's rights violation. This brings us back to the way disabled children and their childhood is socially and culturally constructed.

Definitions and constructions of disability have been influenced by changing historical, social and ideological practices (Connors & Stalker, 2003; Bernal, 2006). Westcott and Cross (1996) draw attention to how social constructions of disability ranging from religious belief as to why somebody is disabled, to negative media representations, as well as how other people treat them, demoralise disabled children, negatively affect their self-image, and influence their life choices. The fact that disabled children are often viewed as passive, rather than active, has numerous implications for social inclusion, as it contributes towards actively excluding disabled children by placing them into residential care, thus violating their rights to live and participate in the family. However, Bernal (2006) argues that society has made progress from beliefs that disabled children are products of evil or changelings, towards an awareness of

oppression and disabled children's rights. In addition the 'new sociology' of childhood recognizes the importance of accounts of their lives and the potential of this micro-perspective to shape any macro-level analysis of childhood (Connors & Stalker, 2003). This view largely informs this thesis and children's accounts are reported throughout and used in formulating policy and practice recommendations.

Considering the situation in the UK Campbell (2002) says that in spite of some progress in realising disabled children's rights, the position is some 10 years behind that for non-disabled children. Disabled children are still primarily seen as children in need of service and protection rather than children who have rights like non-disabled children. Within the medical model framework disabled children are isolated, while awareness about children's rights does not penetrate their world. Bernal (2006, p. 25) says: *'It is only when a social model of disability has been adopted by all in contact with the child that these rights can be met.'* Furthermore disabled children's abilities to make choices often go unrecognized. One of the reasons this happens is because adults fail to establish dialogue with a child, having preconceptions of the child's abilities, and they do not consider the effect of the power relationships between themselves and children. Due to adults pathologising their behaviour, some disabled children exhibit non compliance, resistance and silence, but this does not mean that the children are incompetent (Davis & Watson, 2000).

Oliver (1994) argues that language plays an important role in policy and practice discourse and in justifying segregated provisions for disabled children. It is

inextricably linked to the power exercised by professionals to maintain control and portray disabled people as dependent. Oliver (1994, p. 12) argues that language goes beyond describing experiences or deconstructing the world and practices; that it can also '*enable us to conceptualise a better world and begin the process of reconstructing it.*' For this reason it is indispensable for our understanding of discourses of exclusion and inclusion. Speaking of disabled children as tragic victims, incapable of independence and restrained by their limitations constitutes a discourse of disability as tragedy (Middleton, 1999; Priestley, 2003) which is unlikely to advance inclusion, empowerment or equality. Offering support to disabled children on the basis of charity rather than rights is unlikely to lead to fulfillment of their human rights (Oliver and Barnes, 1998). Chapter five discusses language and discourse in residential institutions and shows how they relate to constructions of disabled childhood and the advancement or obstruction of inclusion processes.

According to Wall (2008) the gap between children's rights and the ideal is not only caused by problems with the implementation of rights. Wall considers the problem more profound because rights are not conceptualised within a framework of childhood, but instead adult-centred issues of autonomy, liberty and entitlement and based on free, equal, or autonomous individuality. This is the reason why children are pressed to the outer edges of the social circle, while protection is granted according to what is convenient for those in power (Wall, p. 541). Wall calls for the regrounding of human rights with emphasis on responsibility to the other and obligation to expand the circle of human relations and humanise societies. This should be achieved not just

by freedom, equality, or rationality, but most importantly by welcoming others in their fullest possible diversity, difference, and otherness.

Furthermore Burr (2002) highlights a problem with UNCRC of being grounded in a modern western concept of the self, a concept of the 'individual' child who needs protection and support. It is expected that this concept is universally and internationally applicable. The concept of rights and autonomy, individuality and self-determination for disabled children is especially problematic, as disabled children are viewed outside the norm of normal childhood (Priestley, 2004). Chapter five shows what the constructs of staff in institutions mean for disabled children and how the discourse of rights simply does not reach some places and some disabled children.

Jones and Marks (1997) argue that the rights of disabled children are frequently denied because the Convention does not adopt the principle of inclusion. This assertion is true to an extent, as the UNCRC does not say specifically that disabled children should be included in society. Nonetheless, it lays the foundation for inclusion. This is evident in the articles on non-discrimination, the right to education, the right not to be separated from parents, re-integration after a child has been separated and participation. Article 23 mentions active participation in the community as well as the fullest possible social integration. It needs to be remembered that the UNCRC was adopted more than 20 years ago and since then the inclusion discourse has moved on and become more directly connected to rights. This is evident in the UN Convention on the Rights of Persons with Disabilities (2006) that is based on principles of the social model of

disability, empowerment and an emphasis that inclusion is a human right. The UNCRPD (2006) also specifies that disabled people have a right to live in the community. Therefore UNCRC (1998) can be used in conjunction with UNCRPD to give more strength to the inclusion agenda. The social inclusion of disabled children is likely to reinforce the fulfilment of rights, as inclusion means accessing services, reducing isolation and having a voice.

Research conducted within the framework of the 'new sociology of childhood' recognizes that children are active beings capable of making choices and constructing meanings in their lives. Connors and Stalker (2003) confirm this when they say that children are very practical in negotiating disability in everyday life activities. In their study the majority of children said they are generally happy and they also expressed a sense of academic and sporting achievement. Kelly (2005) examined disabled children's interpretations of impairments and disability and she argues that children actively develop their own interpretations based on interactions with others. Those adhering to views of children as agents in their own rights, emphasise the importance of children's voices and participation in research and decision making (UNICEF, 2007). In the context of B&H and Bulgaria this thesis makes a contribution to knowledge as it challenges dominant views that disabled children are passive and unable to contribute by taking into account children's voices and experiences in formulating policy recommendations.

### 1.3.3 PARTICIPATING TOWARDS INCLUSION

In examining children's dimensions of social exclusion there is a strong parallel between participation and the social inclusion/exclusion agenda (Morris, 2001; Russell, 2003; Hill et al., 2004). In the UNCRC child participation is given the status of a right, as evident in article 12. It is also integrated in UNCRC through articles addressing rights to freedoms, the right to form associations, the right to protection, the right to family life and prevention of separation from parents, and rights to education, access to information and in an article on adoption. It is explicitly addressed in article 23 in relation to disability. Participation is high up on the rights agenda as well in the social model of disability and is often seen as a way to end discrimination and increase social inclusion (UNICEF, 2007; Tisdall & Liebel, 2008). Participation is important because the needs and concerns of persons with disabilities become clear, when they have the opportunity to raise issues and hold decision-makers accountable. Through participation, persons with disabilities become more visible and persons without disabilities have the opportunity to learn and change – and vice-versa (UN Enable, 2008).

The significance of participation is examined by Hart (1992) who developed the popular concept of the ladder of participation for children and young people to represent degrees of participation and non-participation. The lowest three rungs of Hart's participation ladder are situations where children take part in events or are asked to express their view but without being given the opportunity to understand the issue or given the ability to influence any decision. The most significant participation, according to Hart, is when children have an idea, set up the project and invite adults to

join in on the children's terms. Even though the UNCRC recognizes children's rights to have and express opinions, these rights relate to competency, and in the Convention that is clearly stated. Alderson (2002) says that article 12 is the nearest equivalent to adults' autonomy, but in the case of children it is more about taking part not taking charge, as the Convention is unclear whether the child is the main decider and when (Alderson, 2002). Children's participation is very much conditioned by maturity and this can be problematic for disabled children, especially children with learning disabilities.

Therefore in order to put the participation of disabled children into practice a number of issues need to be addressed, and adults need to play a significant role in making participation possible. Cavet and Sloper (2004) argue that addressing organisational systems such as extending advocacy services, the adoption of inclusive approaches, staff training, as well as education and information, are all needed in order to facilitate the participation of children with disabilities. The examples of successful participation cited show that participation is possible, but in the case of children with disabilities it depends on environments and communications that do not disable. Save the Children (2000) provides a set of simple and cost effective guidelines for child participation which could be utilized by professionals from different service disciplines in Eastern Europe and elsewhere. Some of these organisational principles are utilized across England as demonstrated by Franklin and Sloper's (2006) survey on children with disabilities' participation in social services departments. They found that 60 percent of surveyed social services departments involve children and young people with disabilities in service development and decision making regarding their own care. This



survey revealed that a number of written, visual, verbal, computer, and arts based methods (role play, drama and puppets) are used in order to involve children and young people with disabilities.

After years of enthusiasm, problems with the concept of participation started to surface. Building on the work of the European researchers in the field, Tisdall and Liebel (2008) offer a summary of the problems with this popular concept. They identify a concern about tokenism, lack of impact and consultation fatigue, whilst theoretical work on children's participation is not developed sufficiently to address these challenges. They argue there are different and even opposing definitions and understandings of participation, which can sometimes be seen as an empty concept, with hidden outcomes. In addition Reynaert et al. (2009) emphasise the problem of children being consulted about fairly trivial matters, as well as the inclusion of some children leading to the exclusion of others. Tisdall and Liebel (2008) see functional understanding of participation as an instrument of social integration or social inclusion, whilst the normative understanding takes participation as a value in itself, a tool for self-realisation and emancipation (Tisdall & Liebel, 2008, p.8). However when considering exclusion, the social model of disability and childhood, it can be said that the functional and normative understandings of participation are connected and mutually reinforcing, as inclusion relates to empowerment and vice versa.

Hill et al. (2004) raise the concern that most inclusion initiatives are designed, delivered and evaluated by adults, an approach that contradicts participation philosophy. These

initiatives are focused on reducing the risks of material deprivation with the intention of protecting children, leaving adult-child power relations untouched. They argue that successful policies for combating child exclusion need to respond to '*children's felt needs, rather than to needs attributed to them*' (Hill et al., 2004, p. 80). In addition Tisdall and Liebel (2008) put forward an argument important for this thesis and for understanding the participation of disabled children in non western contexts such as B&H and Bulgaria. They argue that participation needs to be conceptualised taking into account the diversity of children's lives and experience, in order to open a space for under-privileged groups of children to participate. At the same time possibilities for participation need to be explored in contextualised and localised ways (Davis & Hogan, 2004; Tisdall & Liebel, 2008). In examining participation Davis and Hogan (2004) warn of several dangers: assuming that disabled children can only take control over their lives through projects, the over-bearing role of adults in participation projects, pressures placed on children to participate and the danger of creating the 'professional child' who is constantly involved in pseudo-consultation.

#### 1.4. EXPLORING THEORETICAL AND CONCEPTUAL CONNECTEDNESS IN UNDERSTANDING EXCLUSION/INCLUSION

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When talking about 'conceptual homelessness' Qvortrup (2007) referred to the idea of childhood and the 'new sociology of childhood' as a response to this conceptual homelessness. However within this framework initially there was no theorisation about disabled children, so the childhood of disabled children remained in this

'conceptual homelessness'. In addition the social model of disability for a long time gave little consideration to disabled children (Priestley, 2004). This is the reason why Kelly (2005, p. 271) argues: *'disabled childhood seems to enter an abyss between: a) theoretical understanding of childhood because of disability and; b) disability theory because of childhood'*. This brings me to the conclusion that for those of us working in an interdisciplinary field of social policy and sociology there is no well established and comprehensive single approach, theory or concept that can be applied in studying the exclusion and inclusion of disabled children.

This thesis adopts an approach that this can be overcome by exploring connectedness between different approaches, something that is increasingly being done in relation to disabled children (Robinson & Stalker, 1998; Middleton, 1999; Connors & Stalker, 2003; Priestley, 2004; Kelly, 2005; Cocks, 2009). These authors suggest that drawing on the theoretical development of the social model of disability and sociology of childhood can increase our understanding of the lives of disabled children. It can also open up opportunities to develop a framework which will research disabled children's experiences, recognising their abilities as competent social actors (Kelly, 2005). Priestley (2004) demonstrated parallels between childhood and disability arguing that both are socially produced and constructed and historically marked by denied attribution of agency, competence and civil rights. On an international level UNICEF (2007) recognises that human rights, the social model of disability and exclusion/inclusion are complementary models that when tied together can improve the situation of disabled children. Also we will be better able to protect disabled children's rights if we have knowledge of children's lived experiences in their social

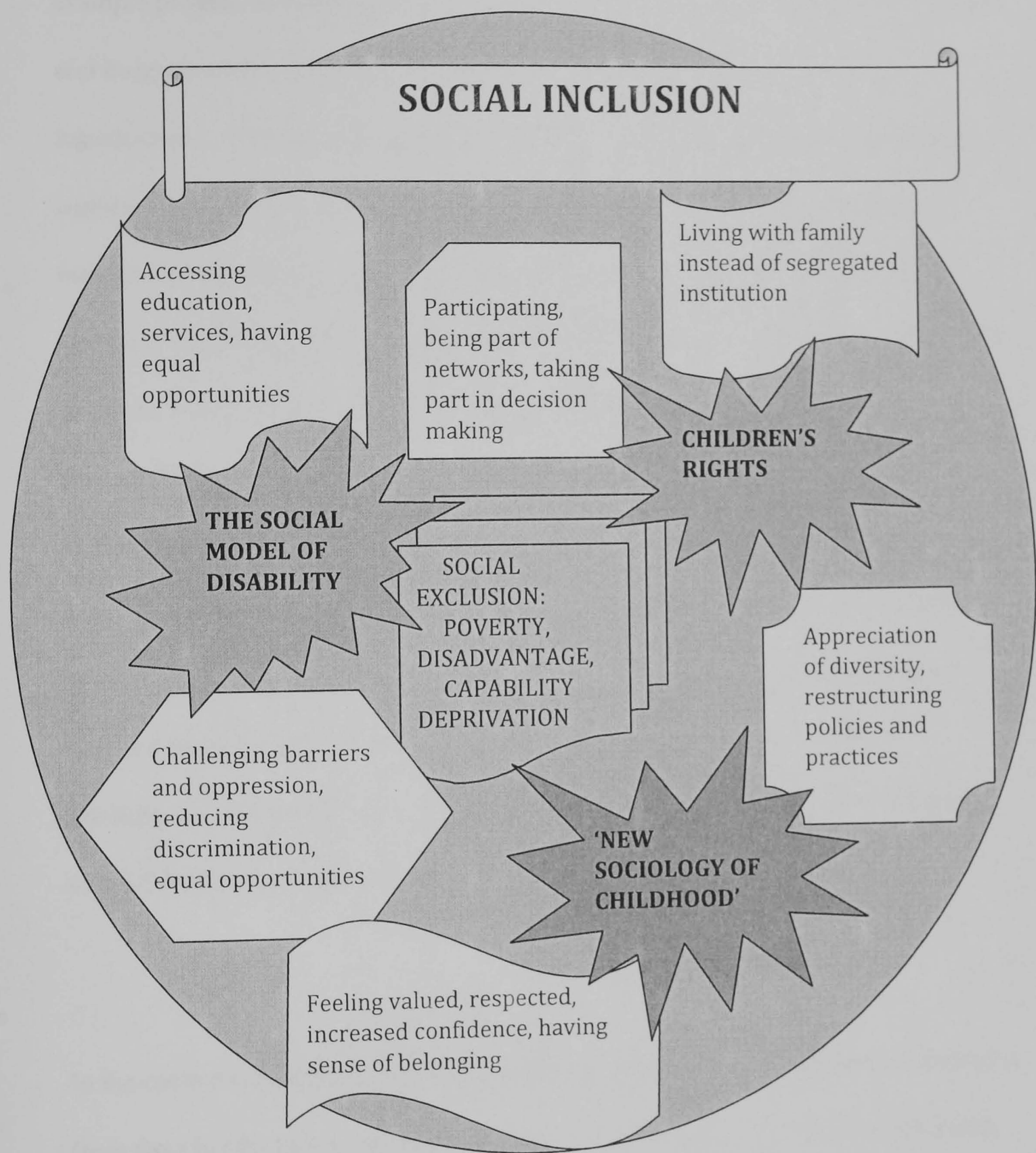
context. This is the reason why this study is informed by several approaches in understanding the complexities of social exclusion/inclusion.

Exploring the fusion between social exclusions, the social model of disability, the 'new sociology of childhood' and children's rights is done in this study with an understanding that each of these approaches have some common principles, as well as differences. All four strands advocate for empowerment, examining the role of society, participation, addressing discrimination and inclusion. However, the social model of disability is about collective voice, and oppression, and there is a resistance among some scholars to incorporating personal experiences as this is seen as individualizing disability and undermining the collective (Finkelstein, 2001; Barnes, 2004). However in line with Middleton (1999), Morris (2001) and Thomas (2004) this study calls for the social model of disability to incorporate personal experience. The rationale for looking into individual experiences is that disabling barriers and exclusion will be better portrayed if they have human voices and stories attached to them. The aim in doing so is to identify and analyse disabling structures, but also to show the impact these have on children and their families. With this approach the thesis shows the lived reality of disabling structures and how these act in the lives of individuals and families to lead to exclusion. It also examines disabling policies and practices, in line with the social model of disability (Oliver & Barnes, 1998).

#### 1.4.1 MULTILAYERED NATURE OF EXCLUSION/INCLUSION

Figure 1 is my model for conceptualising the multilayered nature and complexity of exclusion and inclusion dynamics and processes. The figure demonstrates how conceptual and theoretical connectedness, advocated in this thesis, can be used in advancing the social inclusion of disabled children and their families. As the figure shows, exclusion is a multilayered concept. Children's rights, the social model of disability and the 'new sociology of childhood' are positioned to challenge social exclusion with their influences dispersed in various directions. These concepts aim to combat exclusionary forces by offering understanding that children are active agents in their lives, directing attention to removal of barriers, advocating for increasing participation, promoting equality and other actions that increase inclusion. The figure shows that achieving inclusion is not a process that acts in a linear and orderly fashion. Instead the process is often messy and comes in different shapes and formats, with elements that complement and overlap.

Figure 1. Multilayered nature of exclusion/inclusion



In this thesis efforts are made to understand and show how social exclusion affects individual families and children, but also how it affects disabled children as a social group. Moreover by placing emphasis on the socio-political and cultural context the thesis will show how elements of the social exclusion concept defined in the first

section of this chapter apply to children and families in B&H and Bulgaria. For example poverty and economic inequality is more pronounced in the UK than in B&H and Bulgaria where more people in general live on lower income scales (see introduction). This thesis takes an approach that exclusion and inclusion have some common international characteristics, but also important cultural specificities that require attention. This corresponds to the 'new sociology of childhood' that calls for deconstructing and critically evaluating our views on children, childhood, policies and practices in reference to cultural, social and political contexts and this is done throughout the thesis in reference to the changing economic and socio-political landscapes in B&H and Bulgaria. Also the question of whether and how children have a voice and collective power is differently understood in different cultures and the UNCRC alone or UNCRPD alone cannot change this situation. There needs to be a deeper examination of cultures, attitudes and the appropriateness of these international instruments in any one country, including a review of preconceptions about childhood (Lansdown, 2005).

In the context of B&H and Bulgaria, exclusion is when a child is permanently separated from their family, living in poorly staffed and under resourced residential care, being confined to an institution, having no say in matters affecting him/her. Exclusion is when a child lives with a family, but has poor or no access to resources available to other children, such as education, playgrounds, full health care, does not attend school, has no friends in the neighbourhood. When considering the whole family it can be said that the family is excluded when they are isolated from the community and extended family, experience barriers to employment and discrimination in public places.

Inclusion on the other hand is a process of being integrated in networks, not only networks of other disabled children and their parents, but wider social networks. Furthermore inclusion is being accepted, appreciated, listened to, and having choices and opportunities. Complexity is added when thinking about inclusion mediated through residential care, group homes or special schools. In the context of B&H and Bulgaria this thesis makes a contribution to knowledge by showing how global inclusion and the children's rights agenda is translated where constructions of disabled childhood are informed by specific historic, cultural and socio-political contexts.

Finding a 'conceptual home' is a phrase used by Morrow (2008) to praise achievements brought about by the 'new sociology' of childhood. This phrase seems appropriate to use in concluding this chapter, in which I addressed 'conceptual homelessness' by bringing together several conceptual strands. The chapter reviewed literature on the key sociological/political concepts on which this study and thesis rest: social exclusion, the social model of disability, children's rights and the 'new sociology' of childhood. These concepts are brought together in this chapter in an attempt to address the gap in theoretical perspectives on disabled childhood. This review and the fusion of these four conceptual strands, sets the framework for investigating the exclusion of disabled children and their families in B&H and Bulgaria.



## CHAPTER 2

### POLICY CONTEXT: COMMUNISM, TRANSITION AND DISABILITY ISSUES

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Whilst the previous chapter debated theories and concepts important for understanding and examining exclusion and inclusion, here I will look at the policy context in both B&H and Bulgaria. In the last 20 years both countries have undergone major political, economic and social changes, having moved from socialist and communist ideologies based on a command economy to one rooted in free markets and democracy. Firstly this not so distant past will be reviewed. The need to go back and look at the past of B&H and Bulgaria is grounded in the idea that historical legacies, cultures, political organisations and social interactions are of critical importance in analysing changes in welfare states (Cerami, 2006). This is especially important for Eastern Europe as remnants of the old ideology may still exert influence on the current situation. The second part of this chapter will debate the current political and policy issues and changes driven by EU accession and other significant international pressures and influences.

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#### 2.1 YEARS OF COMMUNISM AND SOCIALISM

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After the Second World War communism was much in evidence across continental Europe, more so in Eastern Europe because of the presence of the Red Army that had

played a major role in liberating Eastern Europe from fascist rule. Even though communism, under the Soviet sphere of influence, dominated the political life of Eastern Europe, there were important variations across different countries. This is especially evident when comparing the Former Yugoslav Republics (Bosnia and Herzegovina was one of six republics) that were largely independent from Soviet influence with Bulgaria that was a satellite state of the Soviet Union. Bulgaria had a unique relationship with the Soviet Union going back to the 19<sup>th</sup> century when the Russians liberated the country from five hundred years of Turkish rule (Deacon & Vidinova, 1992). During the Second World War Bulgaria initially sided with the Axis powers, though switched sides to the Allies in 1944, the year in which the Red Army arrived.

Under the leadership of the Bulgarian Workers party the Monarchy was overthrown and in the following years Bulgaria adopted a socialist constitution modelled on the Soviet Union. In 1955 Bulgaria entered the Warsaw pact, further strengthening its relationship with the Soviet Union (Natek & Natek, 2004). The strong intention of the Soviet Union to control Eastern Europe was evident in the Yalta negotiations in 1945 when Stalin, Roosevelt and Churchill held talks about Europe post-war reorganisation. Stalin's intention was to dominate Eastern Europe, wanting 90 % of the influence in Bulgaria and 50 % in Yugoslavia (Rees, 2008, p. 311). During Stalinist rule (1945-1953) Bulgaria experienced major brutalities and oppression, whilst people lived in fear, isolated from the rest of the world. Due to the debt Bulgaria felt towards Russia there was no critical intellectual underground opposition in Bulgaria towards Russian

dominance, a factor which significantly influenced social policies (Deacon & Vidinova, 1992).

Policies in the Former Yugoslavia were also modelled on the Soviet Union immediately after the Second World War. However in 1948 Stalin expelled Yugoslavia from Cominform (Communist Information Bureau) and Tito started to pursue an independent, liberal minded and anti Stalinist line (Malcolm, 1996, p. 196). At the time Yugoslavia strengthened ties with Western democracies and became heavily dependent on their loans, subsidies and diplomatic support. For a country ruled by the Communist party this position was awkward and the way to justify it came with joining the non aligned movement with Ethiopia, India and Egypt in 1955 (Malcolm, 1996, p. 197). In 1955 Yugoslavian borders were open for the movements of citizens, foreigners and trade. In order to satisfy conditions of the International Monetary Fund (IMF) loans, Yugoslavia had implemented decentralising economic reforms, enabling it to somehow maintain communism while moving away from Soviet influence (Thompson, 1992).

The Yugoslavian independence from Soviet influence has had an effect on the construction of policies. Rejecting Soviet type dominance along with its harsh labour legislation (Swain & Swain, 2003) Yugoslavia introduced what could resemble democratic control and voice in the workplace, promoted through the concept of *samoupravljanje* meaning self-management or self-governance. The idea was to increase workers' participation in decision making and in the management of enterprises and

large companies and thus introduce advisory workers' councils that represented the will of the worker. In this system, workers themselves were shareholders whilst the factory was an autonomous and competitive organisation (Liotta, 2001). At the same time Yugoslav leaders critiqued the Soviet bureaucracy (Swain & Swain, 2003) as well as the Soviet interpretation of Marxism, which led to the positioning of the Soviet Union and Soviet influence as an enemy of Yugoslavia.

#### 2.1.1 SOCIAL POLICES DURING COMMUNISM

Differences between Yugoslavia and other communist Eastern European Countries are important (Puljiz, 2007) however there were also major similarities. State social policies across the Soviet Union and Communist Europe were closely linked to employment. The care of small children and the elderly was heavily institutionalised, whilst education and health care were organised in a centralised and bureaucratic way (Manning, 2004). In communism all policies were social by definition and the state provided free health care, education, housing, employment, public pensions and a safety net (Cerami, 2006). Table 2.1 was developed by Deacon (1992) and summarises the system of welfare across Eastern Europe and the Soviet Union. The overall organisation of welfare is important in understanding the way disability was addressed, and the way families were supported. In spite of numerous benefits the system offered there were some major shortcomings as indicated in the table.

**Table 2.1. A system of welfare across Eastern Europe and the Soviet Union (Deacon, 1992).**

<i>Advantages</i>	<i>Disadvantages</i>
Job security for many	Inadequate or absent unemployment pay
Workers' wages represent high percentage of average wages	Hidden privileges of party state bureaucrats
Free health service (but oiled with bribes and gifts)	Underdevelopment of preventive approach to health. High mortality/morbidity rates
Three year child care grants for working women and the right to return to work (especially in the GDR and Hungary)	Obligation upon women to work and care.
Highly subsidised flats	Sexist division of labour
State-organised social security pension and sick pay system	Maldistributed flats so better off live in most subsidised
Party-state/workplace paternalism	No index-linking of benefits, and work- record heavily regulated. Total inadequate back up of social aid.
	Total absence of right to articulate social needs autonomously from below

On the surface this system might seem egalitarian and ideal for citizens, but in reality was characterised by failures and inefficiencies (Cerami, 2006). According to Deacon (1992) egalitarianism was based on underdevelopment rather than equality, whilst Cerami (2006) argues that the system in the German Democratic Republic (GDR) and Hungary whereby the state provided three year child care grants, lead to the creation of welfare dependency and low incentives to return to work. Within this system of welfare Burke (1994) argues, children with disabilities in the countries of Central and Eastern Europe (CEE) were treated as a problem and often placed in segregated care following medical diagnosis. Pre transition social policies in the countries of CEE did not focus on supporting families to cope with child rearing but rather to remove children from the home in order to make parents fully available for work (Burke, 1994). This was especially true for children with disabilities, but also for all children who

came from families experiencing any form of hardship. Lack of financial and psychological support, as well as non-acceptance by society led many parents in Eastern Europe to send their disabled children to residential institutions. It was not only disabled children who were sent to residential institutions, but orphans and children from underprivileged backgrounds, e.g. Roma children.

However to say that disabled children were placed in residential care to remove them from public sight is an oversimplification (Puljiz, 2007). Some argue that the idea was not to permanently segregate, but to provide care and allow for re-categorisation, as well as further education and mainstream employment (Sarenac et al., 1999). In fact for the same reasons other European countries, regardless of communism, saw institutional care as a way of showing that society cares (European Commission, 2009). In exploring the practices of institutionalisation across the region, Tobis (2000) argues that the systematic institutionalisation of children, as well as bad practices in institutions started long before the Soviet period. Initially these institutions were orphanages and the numbers of institutionalised children fluctuated with social conditions though mostly as a response to the increased number of orphans during wars and famine.

Notwithstanding the above argument, the practice of institutionalisation was undoubtedly strengthened during the period of communist rule. One of the expectations of communist ideology was that socialism would bring about such prosperity that the numbers of needy citizens would decline. This expectation was ingrained in the minds of both policy makers and citizens. This myth of perfection

extended to disabled children who were rendered invisible during their incarceration in institutions. Moreover, surveys and testing (of motor and cognitive development for example) was prohibited. Consequently in a climate of denial, the problems that disabled children faced were only recognized by family and professionals who worked with them (Malofeev, 1998). Vann and Šiška (2007) for example report how in Czechoslovakia during the communist period, issues around intellectual disability were not publicized, while the segregation of disabled people reduced interest in the elimination of barriers to inclusion in society.

By breaking away from Stalin's influence and with the introduction of participatory socialist-self management, Yugoslavia, unlike Bulgaria recognized and acknowledged the need to tackle emerging social problems. Referring to work by Ruzica, Puljiz (2007, p. 71) explains these fundamental changes:

*The doctrine of "social automatism", according to which social problems in socialism will disappear along with economic development and as phrased at that time "building of socialist social relations", was abandoned. The dogma according to which socialist society is a non-conflict one and therefore it has no social problems is abandoned. For instance, in the child protection sector, in addition to classical children's homes, families are introduced as subjects of social protection. As far as the protection of the disabled is concerned, professional and social rehabilitation starts to be applied. Special protective workshops are opened for the disabled...*

The nature of family policies and attitudes towards women in communism can to an extent explain current issues with child care in Eastern Europe (UNICEF, 1999; Zavirsek, 2008). For example during communism, women in CEE were expected to hold full time employment, as well as full and sole care of domestic duties. UNICEF

(1999) reports that women in CEE under communism had higher employment rates than their counterparts in Western Europe and North America, but their workload including domestic duties was approximately 70 hours per week. The idea of women's participation in the labour market under communism was based on the necessity for economic efficiency rather than any concern with equality and independence (UNICEF, 1999). This contrasts with the arguments of Alexandra Kollontai (1920), an influential Marxist and communist ideologist. Kollontai argued that in capitalism children are a burden for proletarian parents, whilst in communism there was more support for the family as responsibility for the child was passed from the family to the collective. The downside of this collective care is that it legitimised the removal of children from families to institutions.

Communism also strongly impacted on the development of civil society. According to Residagic (2006) one of the greatest mistakes of socialism in the former Yugoslavia was to prevent civil society organisations from carrying out charitable and educational activities. This stranglehold on permitted social activities may have stemmed from the fact that the communist party, which itself originated from a grassroots movement, feared the power of any such movement to effect social change. Only organisations that worked on activities officially sanctioned by the communist party were allowed, for example: those supporting government programs and ideology such as anti-fascist women's associations and the children and reforestation project (Residagic, 2006).



During the communist years, in both B&H and Bulgaria, civil society was suppressed, leading to a complete atrophy of this sector with hardly any influence on social policies. Todorova (2000) remarks that in Bulgaria after 1944 only a few NGOs were preserved such as the Red Cross, the Union of the Handicapped, the Union of the Blind and Deaf People and cultural and professional unions of musicians, and scientists. In B&H the NGO sector also consisted of sporadic associations of citizens gathered around issues of common interest and these were mostly concerned with culture and sport. Challenging government bodies or providing a critique to government policies and actions was de facto undesirable during communism, so the above organisations were addressing issues that were seen as presenting no threat to government authority.

#### 2.1.2 SERVICES: SOCIAL WORK AND DEFECTOLOGY

Puljiz (2007) explains that in the early 1950s following the break with the Soviet Union, the Yugoslav republics critically re-examined the socialist legacy and adopted the social work concepts of western countries, preferring a professional, expert approach ahead of simple state control, which meant social problems were no longer hidden, as remained the case in Bulgaria. Families became subject to special protection, whilst professional and social rehabilitation was applied for disabled people, including the opening of special protective workshops. Furthermore unlike the rest of the communist Eastern Europe, Yugoslavia had systematic education for social workers with university education for social work as well as social work centres opening across Yugoslavia in the 1950s and 60s (Puljiz, 2007; USAID, 2008). Bosnia & Herzegovina, which was relatively underdeveloped in comparison to the other Yugoslav Republics, opened their four-year university program in Sarajevo in 1958, but more recently,

social work schools were opened at the University of Banja Luka (2000) and at the University of Tuzla (2004) (USAID, 2008).

In other Eastern Europe countries, including Bulgaria, social work was perceived by the communist regime as “*unnecessary*” and an “*unsuitable activity for petite-bourgeois*” (Zavirsek, 2008, p. 743). Bulgaria therefore seriously lagged behind Yugoslavia and social work at undergraduate and postgraduate level was only taken up in early 1990s with the Bulgarian system of social work developed using the German system of ‘social pedagogy’ (USAID, 2008). Currently case management is the predominant model of social work practice, with an emphasis on social benefits in the public sector (USAID, 2008). In spite of the advanced status of social care in the Former Yugoslavia, Bosnjak and Stubbs (2006) argue that the social services relied on medicalised models of the family and individual deficiencies rather than a commitment to social justice and human rights. This meant that service users were required to fit into existing services. They further argue that social services will incorporate a human rights approach only if fundamental systemic changes take place including changes in the commitments, attitudes and behaviour of service providers.

One characteristic feature of the scientific approach to disability, present in the countries of Central and Eastern Europe and the Commonwealth of Independent States is defectology (UNICEF, 2005). It was developed in Russia during the 1920s when Vygotsky gave it the status of a science (Gindis, 1995). In the years that followed it was adopted in most Eastern European communist countries as a form of rehabilitation and

education for people with disabilities. According to Ajdinski and Florian (1997, p.119) defectology is not synonymous with 'special education', but does include it as one component of a broader and more integrated field which includes aspects of clinical, social, economic and rehabilitative care which when combined forms an integrated approach to treatment. The term 'defectology' is problematic as it implies that disabled people are defective, which besides its potential to give offence also stands in contradiction to the social model of disability (Oliver, 2004). Despite its obvious potential to give offense however, it may still be appropriate to use the term in any discussion of disability in Eastern Europe, if for no other reason than this term is widely employed in current discourse in the region. In addition an adequate and less offensive translation term is simply not available.

Western authors have criticised the practice of defectology, arguing that as a discipline it acts as an obstacle to social inclusion (Des Power & Blatch, 2004). In its original form it was developed from Vygotsky's socio-cultural approach, and conceptualised development as a process emerging from children's social interaction with others (Vygotsky, 1993). Some have argued that Vygotsky's original work comprised part of a social paradigm, emphasising as it did the need for integration (Daniels, 2005). However, as already shown in this chapter, the pre-1989 communist ideology exerted considerable influence on professional practices by creating a climate in which any difference from perceived 'normality' was denied (Malofeev, 1998; Vann & Šiška, 2007). The impact of this was that defectology moved from being a progressive development from Vygotsky's teaching to a discipline that served as an ideological

vehicle which, under the auspices of medicine, produced segregation in tune with the wishes of the communist party elite.

Professional practices in B&H and Bulgaria were based on this now traditional medical/individual approach with its focus on rehabilitation and prevention, simultaneously according professionals power and influence over service users. With professional practices embedded in and influenced by a political climate which created an aura of non-acceptance of disabled children, professionals working with disabled children and adults were encouraged to strengthen segregated provisions and focus on rehabilitation and overcoming impairment. This left no room for integration (Ainscow & Haile-Giorgis, 1998). The changes which the discipline of defectology is undergoing will receive further consideration in chapter six. In the region, professional practices, such as defectology, were developed in such a way that they would sit comfortably with the prevailing notions of childhood constructed across communist Eastern Europe.

### 2.1.3 COMMUNIST CHILDHOOD AND EDUCATION

The power of communist ideology was not restricted to politics, economics, social policies and civil society. During the communist period most countries in Eastern Europe viewed children as a valuable national asset, a safeguard for a future in which they would grow up into responsible communist citizens, ready to take society forward (Stanciulescu, 2010). To varying extents children were viewed as the property of the state, rather than their parents and as such the state reserved the right to

interfere with parenting and assume the responsibility for the care of children (Todorova, 2009; Stanciulescu, 2010). The influence of communism extended into all aspects of social and family life - including the ideologising of childhood. This is poignantly discussed in Ildiko Erdei's (2004) portrayal of the Yugoslav Pioneer Organisation, which I personally experienced as a child growing up in socialist Yugoslavia in the 1970s and 80s. The main goal of the Pioneer organisation was to socialize children into being future 'good' comrades. Similar organisations to this existed in other communist countries, including Bulgaria. The organisation started during the Second World War and ended in 1989 with the commencement of the dissolution of Yugoslavia (Gligorijevic, 2007).

Using a social constructionist framework Erdei (2004) argues that the Yugoslav Pioneers, into which children were initiated at the age of 7, constituted the official exemplar of a happy childhood under communism. Representations of this 'happy childhood' depicted smiling children with their uniform blue caps and red scarves standing in an orderly manner whilst taking the special pioneer vows. Taking these vows included a declaration of commitment in preserving the path of socialism and Tito's ideas; being an honest, faithful, hard working pupil, respecting parents and elders and loving the homeland (Gligorijevic, 2007). With the idea that work makes pupils self-disciplined, little pioneers performed socially useful activities such as cleaning schools, collecting old papers, as well as gathering litter and medicinal plants. Children often attended summer camps that were organised with a military structure, including an early morning salute to the flag and at the day's end a report to the leader comrade (Erdei, 2004). All this illustrates the tendency of the communist state to take

an active role in moulding children outside the realm of parental responsibility in order to create the ideal future communist. Yugoslav communist leaders directed significant efforts into the 'proper' upbringing of children that were seen as the future of society (Erdei, 2004).

Erdei's analysis of the pioneer organisation and socialist childhood contains no simple conclusions as to its success or failure. In spite of the obvious shortcomings to be attached to the 'ideology of the happy child' – one that on the face of it did not leave much room for happiness, childhood memories of different generations of Yugoslav pioneers demonstrate that that this would only partially be true (Erdei, 2004). The education system was also subject to the effects of communist ideology. Children were encouraged to help one another but also to compete and excel academically and in various sports and extracurricular activities. The school curricula were demanding with many subjects and strict discipline, where critical opinions were discouraged especially if they challenged any aspect of the dominant ideology. Education in the communist countries of Eastern Europe has been perceived as one that favours memorization instead of analytical and critical thinking, with premature and over-specializations that may be ill-suited to the needs of a market economy (Melzig et al., 2005). Children were examined without notice and a strict discipline and high standards were imposed, with no allowance made for disabled children.

Due to both the inherent inflexibilities of the system and the influence of ideology, disabled children were largely out of sight. In B&H children with disabilities were

predominantly educated in special classrooms within mainstream schools, as the system of special schooling was not well developed. In Bulgaria however the system of special schools and special residential schools was extensive and a large majority of disabled children were educated in these establishments (Tsokova & Becirevic, 2009). Special schools and residential care institutions will be discussed in more details in chapter five.

## 2.2 POLITICAL AND ECONOMIC TRANSITION

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In the mid 1980s Mikhail Gorbachev, then president of the Soviet Union began a series of political, economic and social reforms, a process called Perestroika. However the failure of these reforms to kick start the Soviet economy combined with civil dissent led to considerable social upheaval. At the same time independence movements in Georgia, Ukraine and the Baltic States assumed greater prominence (Zouev, 1999). The collapse of the communist system began in earnest in 1989 and swiftly spread across Eastern Europe and the Soviet Union. The combination of economic factors, new institutional arrangements and a political consensus around democratic ideas were important factors in producing regime change and the transformation towards democracy (Cerami, 2006, p. 29). Several major events marked this important socio-historic period: for example the Velvet revolution in Czechoslovakia, upheavals in Bulgaria, the fall of the Berlin Wall and the end of the Cold War. A series of mostly peaceful revolutions occurred as Eastern European states broke away from the communist bloc, and the Soviet Union split into 14 republics over a two year period.

Bulgaria, Czechoslovakia, and Hungary achieved bloodless coups; Poland held free elections; East Germany took the first steps towards reunification with West Germany; Romania's revolution was short and bloody where unrest against the Ceausescu regime resulted in the killing of around one thousand protestors and the execution of Ceausescu and his wife Elena (Stokes, 1993).

In short Eastern European states moved from a communist centrally planned political economy to a democratic and market economy. The most basic difference is that in a centrally planned economy the state decides both the prices and what to produce. This stands in contrast to a market economy which seeks to follow the doctrines of classical liberalism (Alcock, et al. 1998) whereby the market is largely free of state regulation, with businesses operating in a competitive environment free to produce what they see as profitable. However in most of the countries the state usually exercises some level of regulatory control making the end result a mixed economy. Previously communist countries did not automatically become democratic or immediately adopt free market strategies, accordingly many have been defined as emerging democracies or as having a significant democratic element such as contested elections and a multiparty political system (BRIA, 2002). These transitions brought with them major changes in welfare provision – moving toward a decommodifying system and a switch from a universalistic social protection system to one based on assessment.

This transition across the Commonwealth of Independent States, Central and Eastern European and Baltic States was not a smooth process for children. In the entire region



children have to varying degrees experienced wars, atrocities, poverty, violence, political uncertainty and complex socioeconomic crises. The transition also led to increases in mortality rates, crime rates, homelessness, child abuse and exploitation, as well as the erosion of public services which were freely available in socialist times. Unfortunately many of the strategies put in place to engineer the transformation to market economies were poorly designed, poorly implemented and badly managed (Zouev, 1999). Cerami (2006) argues that as a consequence the social cost of economic transformation and democratisation that Eastern Europeans have paid and are still paying has been both unnecessarily high and underestimated.

Whilst revolutions were unfolding across Eastern Europe, Yugoslavia was well positioned to make a successful transition to a market economy and multi party democracy. Unfortunately, this did not happen because the appearance of a stable and prosperous Yugoslavia owed more to the machinations of a centralised communist system than to any underlying economic health (Woodward, 1995). Debating the past and present social policies in Bosnia and Herzegovina would be incomplete without an examination of what is undoubtedly the key socio-historic event of this country - the 1992-1995 war. The war in B&H society created a social and economic situation different from the rest of Eastern Europe.

#### 2.2.1 THE WAR IN BOSNIA & HERZEGOVINA

Like other countries of Eastern Europe, former Yugoslavia was undergoing social and political changes. Communist party power was declining, and social problems

previously hidden were being revealed; national tensions, injustices and an unequal distribution of power. Former Yugoslavia comprised six republics with Bosnia and Herzegovina one of them. In the late 80s economic, social and political problems led to a rise in Serbian nationalism<sup>2</sup> and the Federation of the Yugoslav Republic came under intense strain. Independence was first declared by Slovenia, followed by Croatia, leading to a violent response from the Yugoslav army and the outbreak of war. The exit of Slovenia and Croatia from the Federation meant that Bosnia and Herzegovina was left in a country under the domination of a nationalist Serbian agenda. In March 1992 B&H citizens voted for independence in a democratic referendum, soon after which the country was recognized as an independent state by the European Commission and the United National Security Council. Serbian aggression however had already begun (Malcom, 1996). For the next three and a half years B&H was engulfed in a humanitarian crisis not seen in Europe since World War Two (Hoare, 2007).

In April 1992 the Yugoslav's army's operation under direct Serbian control instigated a siege of the capital Sarajevo and the occupation of numerous cities, towns and villages. The newly independent B&H thus faced the might of the Yugoslav army - at the time the 4<sup>th</sup> strongest in Europe. The international community imposed a strict embargo on weapons, effectively preventing Bosnian Muslims from arming and defending themselves (Fink, 1996). Across the length and breadth of B&H its institutions and citizens were targeted in a strategy of systematic brutality comprising expulsions,

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<sup>2</sup> Historical analysis of this phenomenon, and the explanation of origins of stereotypes, nationalism and scapegoating of Bosnian Muslims is well presented in Noel Malcolm's (1996) *History of Bosnia*. Conditions in which Bosnian Serbs collaborated with Milosevic's Serbia in its aggressive policy towards their own Bosnian republics are elaborated in Marko Attila Hoare's (2007) *The history of Bosnia: from the middle ages to present day*.

massacres, and mass killings of Bosnian Muslims, in an enterprise classified by many scholars as genocide (Gow, 2003; Jones, 2006; Shaw, 2007; Blum et al., 2008)<sup>3</sup>.

Current estimates put the total war deaths at 102,622, with the majority of victims Bosnian Muslims (64,036 Bosnian Muslims, 24,905 Serbs, 7,788 Croats, 478 others (Research and Documentation Centre Sarajevo, 2009). Many children as well as adults experienced concentration camps, along with widespread severe human rights violations, including imprisonment, forced labour, torture, and mass rape (Kaldor, 2005). During the war, health care operated on the basis of emergency prioritizing treatment of the wounded. The education of primary school children was either completely cancelled or organised in shelters and neighbourhoods by teachers who remained in the country. The war obstructed the development of social policy (OECD, 2006) and the formal economy, with people reliant on humanitarian aid. *'War in Bosnia and Herzegovina has impinged on global consciousness in a way no other recent war has done'* (Kaldor, 2005, p. 31).

The war in B&H ended with the signing of the Dayton Peace Agreement that divided the country into 2 entities, Republika Srpska (RS) and the Federation of B&H (FB&H). The Federation of B&H is divided into 10 cantons and the District of Brcko (OECD, 2006). This division presents an obstacle in attempts to build a stronger state fit for EU

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<sup>3</sup>Some authors have used milder terminology to describe crimes in Bosnia and Herzegovina, e.g. 'ethnic cleansing' (Mann, 2004).

accession. Furthermore the leadership of Republika Srpska has frequently argued for secession undermining the integrity of Bosnia and Herzegovina as a united state. The country has multiple layers of government with entity level legislatures and ministries, as well as cantonal ministries all serving a social protection and social policy function (Maglajlic-Holicek & Residagic, 2007, p. 150).

The effects of war in B&H were strongly felt by children and families and produced major social problems that the country has yet to recover from. The capacities of the health, social care and education sectors were badly damaged by the war and were left unequipped to deal with the resultant social problems (OECD, 2006). Thousands of children lost one or both parents. For example in Srebrenica around 7,000 men, many of whom were fathers of small children, were killed in the space of few days in the summer of 1995 (Research and Documentation Centre Sarajevo, 2009) leaving displaced and traumatised widows to take care of their upbringing.

Post-war reconstruction aided by the international community and the humanitarian work of numerous organisations after the war created a form of dependency, associated with the social policies favoured by the World Bank and its conditioned loans. The ideas of child centred teaching, community care, family medicine, community based rehabilitation and psycho-social approaches became popular foreign interventions. Projects for war victims' rehabilitation implemented as part of post-war reconstruction began to promote new ways of thinking about disability, but attitudes

to disability have not significantly changed (IBHI, 2007), even though some like (Edmonds, 2005) argued that they have.

### 2.2.2 THE TRANSITION IN BULGARIA

Whilst war was raging in B&H, Bulgaria was undergoing economically, politically and socially a painful transition from communism. As a result of the poor economy and increased drives towards democratisation, communist leader Theodor Zhivkov was overthrown in 1989. In the following year the reformed communists were voted in. There ensued a strong political struggle between the Bulgarian Socialist Party and the Union of Democratic Forces (Natek & Natek, 2004). In the early 1990s Bulgaria undertook economic, fiscal and institutional reforms, in the face of a social and economic crisis that was much more severe in Bulgaria than in other Eastern European countries (Swain & Swain, 2003). At this juncture there were two views on how to proceed with social policy and economic reform, where one view argued for a 'shock therapy' approach and the other for a more gradual one. Both however had a vision of a 'social market economy' a combination of a market economy and the welfare state. Either way the Bulgarian government was faced with enacting expensive social policy measures to tackle the legacy of social problems inherited from the past, as well as new ones created by marketisation and liberalisation in what was initially thought would be a smooth passage from communism to social democratic capitalism.

The measures of social security placed large burdens on the national insurance system and created a deficit of one billion leva in the social insurance budget by the end of 1990s. These social policy arrangements came under close scrutiny by the IMF who proposed a shift in social policy that would cover those who are on the bottom with supporters arguing that an extensive social policy is not economically viable (Deacon & Vidinova, 1992, p. 77-89). Thus as the decade progressed, communist influence in the Bulgarian Socialist Party with its concomitant resistance to the International Monetary Fund (IMF), the World Bank (WB) and the International Labour Organisation's (ILO) influence on shaping social insurance and social assistance (Sotiropoulos & Pop, 2007) eventually gave way to an acceptance that in order to buffer the severe economic crisis Bulgaria would rely on large loans from the IMF. This had major effects on policy development (Cerami, 2006).

In Bulgaria transition was characterised by high unemployment rates, and a concomitant rise in poverty - a major risk for the social exclusion of children and families (Abadijeva, 2005). In the transition to a market economy previously free services were privatised which meant that large number of families, children and the elderly lost entitlements to benefits they once had (Tobis, 2000). With the increase in poverty parents saw residential care as the only place where their children would get at least one meal a day. Consequently there was a significant increase in the number of institutionalised children (UNICEF, 2005).

In the early stages of transition children with disabilities were largely out of sight, although as events progressed the numbers of children with disabilities rose significantly throughout the region, tripling previous estimates (UNICEF, 2005). Some commentators attribute the increases to worsening child health and reduced access to services. Other analysts argue that the increase is due to the increased ability of health professionals to both recognise and diagnose disability in children and to keep children alive. Some believe that the incentive of cash benefits for children with disabilities is a major factor in why there is such an increase in registered disability (UNICEF, 2005). Furthermore in the late 1980s and 90s when residential institutions for disabled children were being transformed and ceasing to exist in other parts of Europe, in Eastern Europe their role became more prominent. These institutions were viewed as a place where children will be protected and given basic care. However UNICEF (2005) argued that some institutions took advantage of the new ideas and connected more closely with communities.

One of the most harmful legacies of the command economies of Central and Eastern Europe and the Commonwealth of Independent States is the reliance on residential institutions in which children with disabilities live in grim conditions segregated from society (Tobis, 2000). The most common reasons for institutionalisation are parental poverty and unemployment, stigma attached to having illegitimate children and the traditional view that residential homes are resource centres where children receive food, care, and rehabilitation. As discussed in the Introduction disproportionately more children of Roma origin are likely to be placed in institutions. The residential institutions in Bulgaria are often isolated in remote villages and only a small number of

children maintain contacts with their families (Bulgarian Helsinki Committee, 2002), which further exacerbates the break-up of families and the marginalisation of disabled children.

### 2.3. CURRENT DEVELOPMENTS FOR DISABLED CHILDREN AND THEIR FAMILIES

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As discussed in previous sections the socio-political developments in the transition from communism were characterised by exclusion, poverty and discrimination for disabled children and their parents. In 2005 UNICEF published a large comparative study on the situation for disabled children in CEE, CIS and Baltic States. This report argues that the practice of institutionalising children with disabilities is still very much present with at least 317,000 children living in institutions across the region (UNICEF, 2005). The study claimed that special education in segregated facilities, based on the practice of defectology, was a main education and rehabilitation approach. Placement in residential care is a practice where children's rights are often violated - children are not consulted about decisions and may even have been lied to (Save the Children, 2003). This research also noted that families with children with disabilities are relatively poorer, often lacking basic support from the state. Even though a rights based approach is currently being promoted across the region, disability is firstly treated as a medical issue and then as a call on social welfare (UNICEF, 2005).



Examining regional data UNICEF concluded that Bulgaria had the largest number of institutionalised children in Europe, with countries of the Former Yugoslavia at the lower end in terms of numbers of children in institutional care. In 2001, in Bulgaria 82% of all registered disabled children were living in institutions (UNICEF, 2005). In B&H on the other hand in 2005 there were only 89 disabled children who were living in permanent residential care (Ministry of Labour and Social Policy of the FB&H, et al., 2006). Amnesty International (2002) reports that the rights of disabled children are severely violated in Bulgaria, not only citing the proportion of institutionalized children but noting that cruel treatment of disabled children is not uncommon. More recent estimates suggest that there are about 7,276 children in residential homes in Bulgaria and this number includes 1,039 children with disabilities placed in residential care (Eurochild, 2010). In addition to the children placed in residential homes, there are 7896 children who study in special boarding schools. These children are mainly labelled as 'disabled' or 'delinquent' and they live in these establishments at least 9 months a year (Bulgarian Helsinki Committee, 2008) However, as argued in the introduction, it is hard to establish how many of these children are disabled, as large number of Roma children attend special schools. Conditions in some institutions in Bulgaria have improved and some have been closed, however human rights organisations are still concerned that more significant changes have not been demonstrated (Council of Europe, 2010).

The reasons why disabled children are often institutionalised in Bulgaria are manifold: absence of psychological and social supports for parents at the point of diagnosis, lack of reliable information and a heavy emphasis on a medical model which invests power

in the medical profession, and results in families being stigmatised (UNDP, 2000). This is compounded by a lack of inclusive educational options and community care, as well as the recent financial downturn in Bulgaria (Council of Europe, 2010). In the EU report on social inclusion for 2008-2010 the Bulgarian government reports numerous problems in relation to addressing disability. As in B&H there is no systematic information at a regional or national level. In B&H there is an absence of systematically structured information about children with special needs at the community level as well as a lack of networking between institutions and organisations addressing issues of disability (Lepir, 2007). Furthermore there is a low level of education and awareness among parents about the treatment, rights and needs of their children. Lepir argues that not only are existing services not properly utilized, but there is also a lack of special education teachers, speech therapists and psychiatrists. Significant numbers of disabled children thus remain unidentified and do not receive any specialised treatment. Usually, in B&H disabled children live in their own families, cared for by their mothers. These families are however, overburdened by the costs of medical and other treatments and lack access to appropriate community resources (Lepir, 2007).

Both Bulgaria and B&H are faced with high levels of social exclusion – particularly of Roma minorities and disabled people. In B&H social exclusion of returnees and displaced people is also notable. Groves (2006) estimates that half of the population experiences some form of exclusion with over a fifth suffering extreme exclusion. These figures are not surprising if considered in the context of the high levels of poverty, unemployment and inadequate participation of citizens, especially children in decision making. Such are the problems that the previous system – euphemistically referred to

by Deacon (1992) as the 'equality of disadvantage', is viewed by many people with some nostalgia. Nevertheless a UNICEF (2007c) report acknowledges that great progress has been made in a short time in reforming the Child Care System in South East Europe, arguing that fundamental changes in mindset have taken place with more local services and the development of family-based non-institutional forms of care. In addition emerging risks for children are being addressed. While praising this progress UNICEF notes that systematic data collection remains a problem, along with issues of coordination, and accountability. The introduction of minimum standards and their monitoring it is argued has to be made an immediate priority.

In the National Report on Strategies for Social Protection and Social Inclusion prepared for the EU, the Bulgarian government claims significant advances in educational inclusion have been made. In the 2006/2007 school year the number of children with special educational needs integrated in the general educational system more than doubled compared to the previous year, while the number of children accommodated in specialized institutions for the period 2005-2007 decreased by 18% (Government of Bulgaria, 2008). UNICEF (2005, 2007c) however does not support this view claiming that reform efforts in South East Europe even though they appear impressive in some aspects have not been sufficient either to significantly reduce the numbers of children being separated from their families, or the numbers in institutional care.

In the report on education in the region UNICEF (2007b. p. 65) claims that *'the legacy of 'defectology', expressed in the continuation of classification committees responsible for assessing*

*and placing children with disabilities, can also serve as a barrier to inclusion'. In Bulgaria however international cooperation has meant that defectology, as well as its associated professional assumptions has been subject to scrutiny and academic debate. However these debates have subsided as the more pressing preoccupation with the 'what, how and who' of inclusion and inclusive education has moved to the foreground (Tsokova & Becirevic, 2009).*

More progress in addressing social exclusion/inclusion in B&H are noted recently with adoption of the Strategy for equalising possibilities for persons with disabilities in FB&H 2010-2014 (Federation of B&H, 2009). This strategy states that disabled people should not be treated as a social category whose needs are exclusively addressed in centres for social work, but as equal members of society, considering that barriers to their participation are removed. This strategy recognised the need for precise definition of disability, as well as the notion of discrimination on the basis of disability. It is interesting that even though the influence of the social model of disability is present in this strategy, the social model is not defined precisely. The strategy only states that in May 2008 the state of B&H decided to adopt a new approach to disability based on human rights and the social model, which represents a holistic view towards disability, including the development and implementation of solutions based on community level and multi-sector approach with participation of all relevant stakeholders.

Another relevant strategy which has been recently adopted is the Strategy for Social Inclusion of B&H (Government of Bosnia and Herzegovina, 2009). This strategy shows

that social inclusion is prioritised as one of the six goals of the B&H Development Strategy 2008-2013. In this document social inclusion is interpreted as the basis for the EU social policies, referring to the EU indicators of social inclusion. Both strategies recognise the social exclusion of disabled people and the relationship between poverty and disability. However no special attention is given to children with disabilities or families with children with disabilities. This is in contrast with evidence about social exclusion of children with disabilities and their families presented in the previous chapter. There is a lack of a clear theoretical framework for studying the exclusion of disabled children which is reflected in policy development.

In recent years there has been more attention devoted to reforming institutional care so that fewer people reside for shorter periods (Stubbs, 2007). As already argued the institutionalisation of disabled children in Eastern Europe presents major obstacles for inclusion, and this is especially true in Bulgaria. The intention is to prevent new children entering institutions whilst making efforts to reform old institutions and reintegrate children back to their families. In B&H deinstitutionalisation is not an urgent policy priority because the proportion of children living in institutions is very low compared to other countries in Eastern Europe. In the Disability Policy Study in B&H, IBHI (2007) argues that while new models have not been developed in B&H the quality of care in existing institutions has been improved, with some institutions developing activities to prepare residents for independent living.

### 2.3.1 RESPECTING HUMAN RIGHTS?

Due to the presence of international organisations, human rights discourse in both B&H and Bulgaria has become prominent. Both countries signed and ratified the UN Convention on the Rights of the Child (UNCRC), and both promote international agendas such as the Millennium Development Goals, Education for All, the Salamanca Statement and Declaration. Bosnia and Herzegovina is an especially interesting case as the Dayton Peace Agreement gave power to the European Convention on Human Rights to override the constitution. In summer 2009 both B&H and Bulgaria signed the UN Convention on the Rights of Persons with Disabilities and optional protocols. This signing came after two years of pressure from disability and human rights organisations and indicates the intention to ratify the Convention in future. Only when the convention is ratified, will countries be legally bound to treat persons with disabilities as subjects of the law with the same clearly defined rights as other people. Ratifying countries will have to adapt their domestic legislation to the international standards laid out in the treaty (UN Enable, 2008). In December 2009 the Minister for Human Rights in B&H was severely criticized for delays in ratification of the convention, whilst disabled people demonstrated in parliament for several days (Dnevni Avaz, 2009). The Convention is now ratified in B&H, but not in Bulgaria. Fulfilling the rights of the convention will require significant changes including the potential closure of special schools (Tsokova & Becirevic, 2009).

The UN Convention on the Rights of Persons with Disabilities (2006) is expected to significantly improve the human rights framework for people with disabilities because

it calls for an end to disability discrimination in all spheres of society (United Nations, 2006). This convention pays special attention to children with disabilities by affirming among other rights, their right to express their views freely, to enjoy all human rights and fundamental freedoms on an equal basis with all children. In addition the convention places obligations on governments to undertake and provide early and comprehensive information, services and support to children with disabilities and their families. This will necessitate changes to the traditional policies and practices employed with children with disabilities in Eastern Europe. For example, observing rights on participation, community living, independence, respect for the family, accessibility, the right to education and health care will increase opportunities for inclusion. Furthermore the convention has introduced an important paradigm shift in understanding disability by stressing disabled people are not objects of charity and medical interventions but active holders of rights capable of making decisions and being active members of society (UN Enable, 2008). Thus the agenda turns from 'impairment' to combating barriers in society in line with the perspective of the social model of disability.

### 2.3.2 THE EU AND THE FUTURE SHAPING OF WELFARE IN B&H AND BULGARIA

The influence of the EU on Eastern European social policy and welfare is growing, even though the changes are implemented through a 'soft approach', without the EU commanding candidate countries to make changes (Lendvai, 2007). Though the EU treats disability policies and issues as the responsibility of individual member states it exerts influence in numerous ways. Through an open method of coordination and the

use of structural funds, countries are encouraged, directed and supported to develop and change social policies in accord with an EU agenda which has social inclusion at the core of its social policy concerns. The EU reinforces the mainstreaming of disability issues, which includes a rights approach, accessibility and policy making with the participation of disabled people.

Furthermore member and aspiring member nations are encouraged to pass anti-discrimination legislation through its open methods of coordination, research, data collection and structural funds (Deacon & Stubbs, 2007). Commonly agreed social indicators and definitions that monitor employment, social inclusion and health care are published regularly in European Union Statistical Agency (Eurostat) and countries are required to bring their systems of data collection into line with the Eurostat database. Member states are required to submit a national strategy and reports on social inclusion every two years. For example Bulgaria signed a Joint Inclusion Memorandum developed with the European Commission, which comprises measures and policy guidelines to combat social exclusion in all the risk groups in Bulgaria, including children with disabilities (Abadjieva, 2005).

Apart from the technical and technocratic processes of accession that are common to countries of Eastern Europe there is a realisation that reform is needed in all spheres of public services provision (Lendvai, 2007). Accession to the European Union influences public policy on a deeper level than mere legal implementation, influencing the construction, dissemination and institutionalisation of rules, paradigms and ways of



doing things (Saurugger & Radaelli, 2008). However in respect to the Europeanization and transformation of post-communist social welfare policies Lendvai (2007) considers the question of which welfare model these countries actually need to develop. She argues that Europeanization is not simply a matter of catching up or modernisation but rather involves the adaptation and wholesale transformation of existing policy structures in countries which have different structural conditions, complex public policy choices, multiple social-economic trajectories and unique institutional landscapes.

Some of the EU requests of candidate and potential candidate countries, in respect of disability, include for example: removal of physical barriers in public transport and buildings access; community based rehabilitation; closing of large residential institutions; and the development of inclusive education with flexible individual plans. The EU also asks candidate countries to develop a flexible system of social care that can address the different needs of citizens in different phases of their lives (IBHI, 2007). In spite of some commonalities there is considerable diversity in the accession process. Bulgaria for example did not improve childcare as a condition of EU membership. Only as part of the “National Strategy for Equal Opportunities for People with Disabilities 2003–2005” has the Bulgarian government set out a series of specific measures related to education aiming to improve education for children with intellectual disabilities (Open Society Institute, 2005). However as Lendvai (2007) claims, in the processes of accession for Eastern European countries, the EU is not overtly focused on social policies, though this may change once a country has gained membership. This has been the case with the Bulgarian government’s relations with the EU on social inclusion issues (Government of

Bulgaria, 2008), for example its use of structural funds to encourage community care and deinstitutionalisation (European Commission, 2009) and the development of a National Report on Strategies for Social Protection and Social Inclusion 2008-2010, intended to align Bulgarian social inclusion policies with the EU (United Nations, 2009).

In Bulgaria the practice of outsourcing social services initiated during the EU accession processes has gained significant support in recent years and is seen as a way to increase flexibility, reinforce the role of NGOs and improve the quality of services (UNICEF, 2007c). The process of outsourcing is however not without problems. A reliable relationship between financing and resultant quality has not been established, and there is little demonstration that municipal authorities actually have the requisite capacity to manage and monitor social services. Added to which is a lack of trust in the capacity of the NGO sector (UNICEF, 2007c). Outsourcing is an important process in care reform and will be discussed again in chapter six – this time from the perspectives of the participants who are dealing with challenges of outsourcing of services. In short then, with considerable diversity in the accession process and a lack of research on the new social policies that are emerging from accession there is a need for a more comprehensive framework to address both the accession process and the impact of the EU on post communist social policy (Lendvai, 2004).

The EU is not unique in influencing social policies in the region. The World Bank and International Monetary Fund exert a neoliberal influence seeking to focus B&H and Bulgaria's efforts on increasing market efficiency and employment, whilst reducing

cash benefits (Deacon, 2000). This has been in part embraced and in part resisted by national policy makers (Deacon & Stubbs, 2007). Still, in relation to social inclusion, Stubbs (2007) found that all agencies have a broad commitment to inclusive, client centred approaches to child care policy through a range of community services. These agencies bring professional and financial resources and have political power to influence an inclusion agenda. However Stubbs argues that efforts are needed to improve planning, synchronisation and promote an efficient division of labour among these various organisations. Furthermore all agencies agree on the need to reform institutions to reduce the number of service users and move to shorter periods of residence with an emphasis on preventive, rehabilitative and respite services (Stubbs, 2007, p. 7).

This chapter set out the structure and context in which changes in social policies and practices in the field of disability are taking place. The thesis follows Jobert (1996) in embedding international comparisons within an appropriate socio-economic context. Historical differences and similarities between B&H and Bulgaria, presented in the current work, are informative in understanding the situation for children with disabilities now. Current differences related to the EU accession, are also shaping inclusion policies and the situation for children with disabilities. The perspectives given by the participants in how the EU shapes social policies are presented in the later stages of the thesis. The differences and similarities between B&H and Bulgaria on issues of community care, residential care, available professional services and overall situation for families are compared throughout the thesis.

# CHAPTER 3

## 'EMANCIPATORY' RESEARCH WITHIN A SOCIAL POLICY FRAMEWORK: A METHODOLOGY

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So far the thesis has presented the study aim and outcomes and placed them in the appropriate conceptual and theoretical frameworks for examining the exclusion/inclusion of disabled children and their families. Chapter two sets the problems of exclusion in both B&H and Bulgaria in the context of their respective histories, economies and socio-political transformation. This chapter will now examine issues associated with conducting the research. The comparative focus of this study provides fresh insights, leads to a deeper understanding of issues, sharpens the focus of analysis, identifies gaps in knowledge that prevent cross-national comparisons and suggests future research (Hantrais & Mangen, 1996). In conducting cross cultural research, attention has been given to potentially problematic issues associated with different language, concept non-equivalence and definitions and accuracy of translation (Jobert, 1996; Hantrais & Mangen, 1999; Harzing, 2005), as discussed in this chapter.

### 3.1 STUDY FRAMEWORK

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Since one aspect of the study aims to make recommendations and critique current policies it can be subsumed under the auspices of policy research. This kind of research as Etzioni (2006) suggests deals with examining the major facets of social phenomena;

in this case exclusion of disabled children and their families, with the concomitant intention to suggest different policy options and recommendations for addressing the problem. In addition, the study examines the efficiency with which existing policy decisions are implemented and therefore may also be considered within the remit of applied research. A further aim has been to produce rich qualitative accounts of the situations facing families with children with disabilities in the two countries. This was made possible by the theoretical framework employed which depicts reality as socially constructed, and embraces both the situational constraints present and the relationship between researcher and researched (Denzin & Lincoln, 1998). As such the effort has been made to understand the revealed experiences, meanings and understandings from the point of view of the actors who embody them. Recognising the existence of multiple realities is characteristic of both constructivist and interpretive approaches (Denzin & Lincoln, 1998).

The methodology was informed by the premises of 'emancipatory' disability research, which is in line with my overall conceptual framework based on the social model of disability, fulfilment of the rights of those who are oppressed, whilst also uncovering social barriers and discourses contributing to oppression (Barnes, 2001). However accomplishing an emancipatory approach in B&H and Bulgaria was challenging for several reasons; there is a lack of understanding of the social model, disabled peoples' organisations are underdeveloped and there is an overall dearth of disability studies. Still, efforts were made to incorporate emancipatory principles as much as possible.

Throughout the study, efforts are directed at consulting with and incorporating the perspectives of children with disabilities, their carers, parents and disabled people's organisations. In addition their expressed willingness to use this work in advocacy activities to directly challenge specific forms of exclusion, as expected in emancipatory disability research is noted (Zarb, 1997). In spite of being situated in a framework which is both political and ideological, the work will not eschew evidence based interpretation and will aim to demonstrate rigour of analysis (Seale, 2004).

#### 3.1.1 POLICY RESEARCH

This comparative research with a strong policy orientation does not employ a set of specific methods or methodology of its own. However unlike other academic research, it is based around what may be termed a policy cycle - understanding and defining a policy problem, formulating policy, examining implementation strategies and evaluating outcomes (Rist, 1998). As an explicit aim of this work is to contribute to policy making several issues are examined – and discussed with participants:

- how policy problems are conceptualised on the ground
- what policy tools are being developed
- how services delivered reflect policies
- how institutions responsible for policy delivery cope with demand

Unlike the traditional scholarly position, policy research is often seen as partisan and as such is open to the criticism of being prone to preconceived ideas and seeking

examples that support favoured theories (Silverman, 2004). I made specific efforts to enter the field with an open mind which allowed for what Silverman (2006) calls the 'revelation of surprising facts', and new ideas that challenge pre-existing notions. The aim, in accordance with Finch (1999) is producing technically competent, rigorously and professionally analysed and interpreted policy-oriented qualitative research.

In line with policy research practice (Young & Quinn, 2002; Etzioni, 2006) the thesis aims to offer practical and feasible recommendations, operating within existing frameworks and opportunities, so that policies and practices can be steered towards inclusion. As such major legislative changes are not required for positive change to be seen on the ground. When formulating recommendations policy researchers need always to keep one eye on the longer term economic and budgetary consequences and the effect any proposed policy solution might have on families and social relations. This will necessitate a policy research orientation that is eclectic (Etzioni, 2006). For this reason the micro, macro and meso relationships and issues that contribute towards exclusion have been considered. In addition by including families and children living in widely different circumstances a wide range of options and actions can be proposed so that inclusion strategies account for issues across rural and urban areas, traditional and single parent families as well as children in institutions.

Etzioni (2006) stresses malleability as a key consideration in policy research, as it needs to take into account resources, perceptions, and changing public attitudes over time.

For this reason chapter two deals with the socio-political/economic changes as well as a

range of current issues that influence these e.g. EU accession, the international agenda and international NGOs, and the struggle to overcome a legacy of exclusion. Etzioni (2006) also argues that policy researchers must not forget that social relations and attitudes – the hearts and minds of populations - are not so malleable and that therefore proposing rapid and extensive change usually does not work. Relevant in the context of exclusion/inclusion is what Crossley and Watson (2003, p.39) regard as the tendency of '*policy makers worldwide to identify global problems and to seek and implement global solutions as if one model fits every situation*'. One result of this they suggest is a decontextualisation of practices from local culture. In this work therefore I have argued against the use of a single global model in preference whenever possible to local solutions based on local practices.

This research does not aim to give a general presentation of the situation for children with disabilities in B&H and Bulgaria, since any attempt to do so would probably resemble an official view that is in many cases significantly different from what is happening in practice. Support for avoiding presentations of national perspectives is given by Ainscow and Haile- Giorgis (1998) when writing about special needs education in Eastern Europe. They draw attention to two pitfalls of comparative national presentations: the idea that there is a single national perspective and the notion that practice can be generalized across countries without attention to local context and meanings. Therefore in describing the context and issues of social inclusion in B&H and Bulgaria I will discuss some tendencies and practices that appear to guide developments in this field, without an ambition to give a definitive national presentation.



### 3.1.2 INSIDER OR OUTSIDER IN RESEARCHING EXCLUSION OF DISABLED CHILDREN AND THEIR FAMILIES

Policy and practice changes in relation to children with disabilities in B&H and Bulgaria have failed to receive appropriate critical reflection, something that I was acutely aware of during my own time working for an international NGO in South East Europe. I experienced firsthand large discrepancies between rhetoric and action, with power struggles between local and global agendas, dominated by powerful international agents. The work of international organisations and donors has too often consisted of office administration, meetings and biased assessments with an almost complete absence of the voices of children and parents, for whom 'all the work was being done'. This practice of course is not only confined to Eastern Europe (Crossley & Watson, 2003). My impression is that development and implementation of inclusion strategies in Eastern Europe is happening very fast - perhaps too fast – without sufficient time taken to reflect, consult or evaluate current policies or practices around inclusion. This study aims to contribute to this hypothesis by conducting in depth qualitative research.

Historically disability research has been dominated by medical and academic models (Barnes, 2001) which have been used to justify segregation policies and marginalisation whilst some non-disabled researchers have contributed to this oppression (Stone & Priestley, 1996). As the British disability movement has grown, suspicions of non-disabled researchers have been voiced. Emancipatory research does not reject a role for non-disabled researchers but suggests that they need to follow an agenda set by disabled people (Shakespeare, 2006). In Eastern Europe disabled people's organisations

are still not politically strong and it is usually non-disabled people who research disability related issues. Whilst conducting research in B&H and Bulgaria nobody ever raised the question of my status as a non disabled person, instead it was commented on positively on several occasions '*someone cares about our children*' (parent, B&H). This indicates how oppressed disabled people are and how marginalised disability research is in B&H and Bulgaria. However within the constraints of this situation I used every opportunity to discuss directly the research, methods used and their potential with disabled people's organisations from Eastern Europe, as well as drawing on practices of emancipatory disability research from the literature.

How different researchers' positions influence the research process was also subject to considerable reflection both during and after fieldwork. Being a native Bosnian, comfortable with the system, being able to communicate with informants in our native language, being familiar with terminology and cultural norms all implied an insider status (Rubin & Rubin, 1995) and informants frequently referred to me as "one of them". Whilst this makes access, communication and understanding of the cultural and political context easier and productive for data collection, I constantly had to guard against 'going native' and identifying with participants in their settings, and instead remain on the other side of the researcher's lens as suggested by Delamont (2004).

Even though I was a foreigner in Bulgaria, some historical, socio-political, cultural and linguistic affinities that are embodied in a Balkan context (Todorova, 1997) were

experienced as a connection with participants. I was not a complete outsider.

According to Filep (2009) pre existing knowledge about different ethnic and cultural concepts and affiliations can help in engaging with participants. Reflecting on the insider/outsider position brought to light the complexities of these issues. It is not something that can be explained in fixed categories, i.e. in terms of being native to one country. There are other factors that influence this positioning. For example I cannot claim group membership with parents of disabled children, as I am not a parent myself, therefore in this respect with these participants I was an outsider in both countries. With NGO workers and people from international organisations, because of my own experience of working in these settings I was more of an insider.

Conducting this study made me aware that the position of both insiders and outsiders affords considerable advantages for deepening our knowledge of the human experience of any given context (Corbin-Dwyer & Buckle, 2009). Finally, on reflection I realize that my relationship to the topic of social exclusion has been influenced by my own personal experience of being a refugee, because it was a time when I became painfully aware that exclusion is something that happens to us rather than something we choose, as pointed out by Atkinson (quoted in Phipps & Curtis, 2001, p.2). Doing policy, cross- cultural research whilst respecting the emancipatory disability paradigm involved considering and negotiating the methodological issues debated here.

Semi-structured individual interviews were the main research methods used. These were complemented by the use of three focus groups and unstructured observations recorded in a fieldwork diary. Selection of informants was based on purposeful and theoretical sampling strategies. Miles and Huberman (1994) consider the design of a study can be 'loose' or 'tight' with, they suggest, the former for exploration and use in unfamiliar territory. A tight design is to be preferred when the researcher is already familiar with the setting, has already defined their concepts and seeks to come to an explanation or comparison between cases. In the present work a diversity of settings and informants, as well as a degree of familiarity with the field, informed and largely dictated the research approach. As a native Bosnian speaker, a tighter structure worked better in the Bosnian context, whilst in Bulgaria, my presence as a foreign researcher entailed a looser approach was more appropriate. As such the overall work does not fall exclusively under the umbrella of either approach.

#### 3.2.1 ACCESSING AND SELECTING PARTICIPANTS

The fieldwork phase of this study lasted from July 2007 to October 2008. During this period I visited B&H and Bulgaria eight times in total. The length of these visits varied from 7 days to 2 months. Fieldwork began in B&H in July 2007 when the first interviews were conducted and significant networking with various organisations took place. The initial five interviews were treated as pilot interviews and as a way of introducing gatekeepers and potential participants to the study. In initial stages of the

research a network of friends, family and colleagues was utilised in accessing participants - a strategy suggested by Taylor and Bogdan (1998). During the pilot stage, relationships were built with several disability organisations eager to recommend other people from their work circle or from outside.

In order to gain access and learn about professional practices, views and issues in residential care, there was prolonged involvement with one residential care home in B&H. This comprised a series of pilot interviews at the beginning of the research, interviews with children, follow-up interviews with different members of staff and numerous informal conversations with staff and residents. On one particular day I participated for the whole day in a ceremony marking the opening of their new unit and at this event, because of the unplanned absence of the official translator, I was asked to translate speeches by the director of the institution as well as foreign donors. This created considerable trust between the staff and myself and helped in gaining access to interview children.

Sampling choices evolved through successive waves of data collection with careful ordering of multiple cases along a key dimension in order to make powerful explanation more likely (Huberman & Miles, 1998). For this reason the research relied extensively on a purposeful strategy - a procedure whereby the researcher, on the basis of informed judgement, makes a deliberate attempt to select cases or individuals that are representative of the population (Gobo, 2004). Merkens (2004) argues that classical qualitative investigation is interested in what is special; therefore the informants were

selected on the basis of their special characteristics: being a member of a family of a child with disability, being a child with a disability or a service user controlled organisations, and for professionals, having involvement with health, social, or educational provision for children with disabilities.

A purposeful strategy was also suitable for selecting focus group participants, as this permits the selection of people with a key relation to the topic (Tonkiss, 2006).

Accordingly the aim was not to select people representative of a wider population, but people with professional or personal experiences, views, and knowledge of disability issues among children and young people. As, Gobo (2004) argues this purposive strategy maximised variations and enabled access to different situations. For example, children with disabilities living in very different circumstances were interviewed, including children living in residential institutions, in a foster family, at home with a single mother, and with grandparents. Furthermore, the mothers who participated in the research were far from being a uniform group. The severity of their children's disability differed across the sample, whilst some lived in a single parent household, and some were unemployed.

Even though a purposeful strategy was the main method of participant selection, in order to pursue emerging themes theoretical sampling was also used at times. This, according to Seale (2006) involves choosing cases or people to study with the view of challenging, broadening or changing the existing theory to incorporate new phenomena. It included locating people in rural areas or particular informants with

different positions, such as a former policy maker. Theoretical sampling therefore increased variation among the sample, identifying deviant and diverse cases. It also enabled development and testing of emerging analytical ideas (Walsh, 2006). Sampling was also facilitated by networking with various organisations and individuals that occurred through informal meetings and communications with representatives of organisations, as well as through attending conferences and meetings. This prevented reliance on one organisation for selecting the sample, thus increasing variation among individuals and in their views and theoretical positions.

### 3.2.2 PROFILE OF PARTICIPANTS

The number and profile of participants can be summarised as follows: parents and carers of disabled children (N=23), disabled children (N=7), government policy makers (N=6), practitioners in various settings (N=17), representatives from non-governmental and disabled peoples' organisations (N=8), representatives from international organisations (N=3). Variation among participants was especially sought, so that research included participants whose roles occasionally overlapped, this being true for parents of disabled children who worked in parents' organisations (see appendix two for detailed tables with participants) and table 3.1 for sample summary. Accordingly during interviews they often moved from talking about their organisation to reflecting on their experiences of being the parent of a disabled child. In discussing policies and practices they frequently talked from the perspective of a parent.

Table 3.1 Participants

Sample	Number
Children	7
Parents and carers	23
Government policy makers	6
NGO, INGOs and disabled peoples' organisations workers	8
Representatives of international organisations	3
Professionals –social workers, defectologists, school principals	17

Achieving comparability of samples in cross-national research is a major challenge (Hantrais & Mangen, 1996). Efforts were made to ensure as closely as possible comparability across settings and between individual participants. Finding an exact match was difficult but several key dimensions for comparability were included. The research took place in capital cities, as well as two other major cities and two small towns/villages. The places with inclusive orientation such as day centres as well as residential special schools were visited in both countries. Comparison was however difficult to achieve with disabled children, as access to them was restricted, especially in Bulgaria. Gatekeepers, especially in residential places were not in favour of me talking to children and even when they agreed no time was given for preparation. This was negotiated on the spot in B&H, however in Bulgaria it was made more difficult by the obstacle of a language barrier. Interviews with children will be further discussed in section 3.3.2.



### 3.2.3 ETHICAL CONSIDERATIONS

There is no single theory of ethics that can provide clear guidelines, instead the researcher is responsible for choices (de Laine, 2000) that are based on moral, political and epistemological positions that need to be negotiated within different cultures (Kelly & Ali, 2006). For this study the British Sociological Association and National Children's Bureau ethical guidelines were followed. Ethical approval was given by the Open University Material and Human Participants Committee. Since the research involves contacts with vulnerable participants and children the researcher requested and was granted an enhanced disclosure from the UK Criminal Records Bureau. As suggested by the Committee, support within the social care and psychological services in both countries was identified in case participants revealed abuse or became distressed whilst being interviewed and needed psychological support.

The majority of the participants were sent a study information sheet in advance (see appendix 1) otherwise information was given over the telephone. Before the interview time was taken to explain the study, my background, the university I was from, what participation would entail and what the plans were for disseminating results.

Participants were assured that they could decline to participate at any point during the interview or withdraw their interview afterwards. Ryen (2004, 2008) draws attention to the influence of culture on ethics and the need to reflect on the western ethical considerations for privacy and the belief that protection comes with signed documents. Ambivalence by several informants to signed consent was noted, and it was felt that the issue introduced an unwelcome dose of officialdom in the interaction. It was felt as Waldrop (2004) suggests that real consent was not the paper signing moment but the

constant process of negotiation between researcher and informant. Besides as Shaw (2008) notes, in qualitative research participants are not always sure when a researcher is working and when they are taking time out. For this reason all participants were informed that the data from our informal conversations and observations of premises and activities will be used to complement the data gathered in interviews.

Furthermore there were occasions where achieving privacy was not always possible and insisting on it would have been considered culturally inappropriate (see Ryen, 2008). In accordance with participants' preferences a few interviews were conducted in restaurants or café's (during quiet times) and on two occasions participants' colleagues were present in the room during interview. However, the main dilemma occurred when at the start of an interview with one family the informant received unplanned guests - a neighbour and her son, a practice that is usual in Bosnian villages and declining hospitality for any reason would be considered rude. When this happened I carefully offered to reschedule the interview, but my informant assured me that they were comfortable talking in front of the neighbour.

In working with children, obtaining consent was an ongoing, reflexive effort, taking a situated and negotiated approach to ethics (Renold et al., 2008). While it was the professionals and parents who officially consented to the research, time was taken to explain to each child, in accordance with their understanding, what the research entailed whilst also giving them the opportunity to decline participating if they so wished. Care was taken to assure children that they were not being judged or assessed,

as I was neither a social worker nor a teacher. They were also assured that they could stop the interview at any point and for any reason if they did not understand something or no longer wanted to take part. In addition children, as well as some other participants did not seem to understand the need for pseudonyms. Nevertheless, due to the sensitivity of some information and the personal issues discussed, the participants' real names were not used in the thesis.

Ethical dilemmas were present during the data interpretation stage as several participants expressed views that were disempowering to disabled children. Presenting these participants in demeaning and unflattering ways would have meant betraying the trust they invested, and cause hurt as this picture would not reflect their vision of themselves (Fontana & Frey, 2005). The major challenge was to reduce this ethical problem by being critical and explanatory not to individuals but toward the discourses they were operating within and to acknowledge the power of the social and political context on the ways individuals behave.

Ethical considerations stretch beyond confidentiality and anonymity and include the question of whose agenda the research serves (Lincoln & Guba, 2003), something that is very much a matter of concern in disability emancipatory, child centred and feminist research. Participants offered suggestions as to how this research could be used to inform policy, to support awareness raising and in general to contribute to improving the situation for disabled children and their families. This accords with Lincoln's (2002) view that research should serve the needs of the community in which it was carried

out rather than simply contributing to academic knowledge. From the start participants were informed, and strongly supported the idea, that efforts will be made to disseminate and publish as much as possible from this research. However, they were also informed that publishing endeavours are not guaranteed and no promises can be made.

### 3.3 METHODS: INTERVIEWING CHILDREN, ADULTS, ELITES

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The interviews in this study can be defined as semi-structured (Robson, 2002), or open interviews (Hopf, 2004). Semi structured qualitative interviews are suitable for exploring in some depth, people's experiences, values, attitudes (Byrne, 2006) past events, motivations and reasoning around concepts (Drever, 2003). This makes it appropriate for eliciting views on social inclusion and exclusion, policies and practices around disability. Furthermore Byrne (2006) argues that qualitative interviews allow for investigation of sensitive topics and for exploring the voices and experiences of people who have been ignored, surpassed or misinterpreted – an apt description of the disabled children, their parents, and some of the practitioners in this work. According to Byrne this style is compatible with an ontological position which regards peoples' knowledge, values and experiences as worthy of investigation. Children were asked about their experiences of school, friendships, places where they live, their likes and dislikes. Other informants were asked questions in accordance with their position and place of work. The aim was to access a variety of views on as many relevant topics on

issues that can be related to disability as possible and to examine opportunities and obstacles for inclusion as they are seen from different stakeholders' perspectives.

### 3.3.1 QUESTIONS AND INTERVIEWING PROTOCOL

A series of topics and questions were prepared in advance for different groups of people, and were used to open discussion and to provide further prompts rather than a structured interview guide so as not to restrict the interviewee's response (Bryman, 2004). For example parents were asked about negotiating disability related issues at home, about their and their children's opportunities and obstacles for inclusion. Even though questions and topics were formulated in advance these were loosely administered and both the wording and question order were altered (Bryman, 2004) in harmony with the conversation, to ensure greater flexibility. Only open-ended questions were asked because these are more flexible, allow interviewees to go into greater depth and can clarify possible misunderstandings (Cohen et al., 2000; Byrne, 2006). Indeed explanations were offered immediately whenever it appeared that informants did not understand or misunderstood a question. In addition, care was taken to avoid what can be seen as double barreled, biased (Robson, 2002) or leading (Bryman, 2004) questions. This can be seen from the interview protocol in appendix four.

When interviewing guidelines commonly used by researchers were followed; participants were given time to express themselves, they were not interrupted, questions were asked in an understandable format and the approach was adjusted so

that interviewees were encouraged to talk, but around the subjects of the research (Byrne, 2006). Effort was made to establish rapport and build trusting relationships with participants, which is important for developing informed research (Fontana & Fray, 2005). Furthermore the timing and location of interviews was adjusted according to what informants preferred. Some interviews were held in organisations where informants worked, some in quiet cafés, some in family homes. Issues of ethics, informed consent, data use, and confidentiality were discussed at the start. Participants were aware that they could stop an interview at any time without any consequences or that they could later withdraw their participation. Refreshments were provided throughout the interviews.

A majority of the interviews were audio recorded and were transcribed fully providing a permanent record of the interviews (Arksey & Knight, 1999). Most interviews were transcribed soon after recording, which according to Wengraf (2001) is a good way to retain the research experience. Interviews conducted in the Bulgarian language were transcribed by the translator, but these interviews were listened to again by myself (I possess a basic working knowledge of Bulgarian) and clarifications were discussed with the interpreter. In transcribing interviews instances of laughter, longer pauses and expressions of sarcasm which provide an emotional accompaniment to the dialogue were noted in different print with a short description, whilst in the focus groups care was taken to identify who said what (Bryman, 2004).

Ann Oakley (2003) challenges the 'masculine' style of interviewing that emphasises objectivity, strict professionalism, friendliness without involvement and avoiding responding to informants' questions. In my research I have chosen to adopt an approach which does not shy away from friendliness, involvement and investment of personal identity as Oakley argues. The interview is a type of social interaction where the behaviour of both interviewer and interviewee necessarily combine to form the relationship which shapes the interview (Fontana & Frey, 2005). Hence the style of communication and level of friendliness is not only decided by the researcher but also by the respondent. Differences in respondents' ages, gender and social position can be expected to produce differences in interviewing style and dynamics. This does not preclude a role for the expectations and preconceptions that respondents will have as to what an interview is supposed to look like. Necessarily the nature of the interview will flow from the intended stance of the interviewer and how this interacts and responds to the expectations of the interviewee.

### 3.3.2 INTERVIEWING CHILDREN WITH INTELLECTUAL DISABILITIES AND COMMUNICATION IMPAIRMENTS

Altogether seven disabled children were interviewed. Three children were interviewed together with their families. The other four children live in a residential home in B&H where the interviews took place. Four children were aged between 7 and 10 and three were between 14 and 17 years old. The children in the residential institution had different levels of intellectual disability but no physical disability. Among the children living with families, one child had Down's syndrome, one child a severe form of cerebral palsy and one boy emotional and learning difficulties.

It is well documented that children who have significant communication and/or cognitive impairments are often excluded from research that concerns them (Morris, 2003; Rabiee et al., 2005). A wish to exclude these children was expressed by professionals in the residential institution, but not by the parents and the carers. In residential institution in B&H professionals claimed that the children with intellectual disability are incapable of giving meaningful responses and contributing to the research, but after some negotiation permission was granted. This permission however did not mean that access to children was unlimited, instead gatekeepers contended that organising these interviews caused inconvenience to staff. Efforts were therefore made to keep any disruption of their routine to a minimum.

A member of staff, a teacher well known to children, was assigned to help. The advantage of this was that the children were not alone with someone unfamiliar, which is important when conducting research with vulnerable participants (Liamputtong, 2007). However it should also be born in mind that the presence of the teacher may act as a barrier, preventing children from expressing themselves fully. Individual interviews instead of focus groups was the preferred method because children's abilities varied significantly, some being more communicative than others, and it was likely that in the focus group some children would not get a chance to express themselves. After spending some time interacting with ten children in the class the teacher and I agreed which children to ask if they wanted to take part. This decision was made based on the children's communication ability, and positive interaction with me. The teacher was present during the interviews, getting involved only if a child made unclear statements or made reference to something unfamiliar. It was not



completely possible to access all the information about a child's life from a child with intellectual disabilities, so information from the teacher was used to fill in the missing gaps, an approach that has often been used (Morris, 1998; Celinska, 2004). The teacher was explicitly not asked about the attitudes, beliefs and perceptions of the children, as proxies can not accurately represent these (Liamputtong, 2007). Before the interview started the children were introduced to tape recording and given an explanation of how it was to be used. Care was taken not to ask potentially emotionally upsetting questions and none of the children got upset during any of the interviews.

Booth and Booth (1996) have identified several barriers in conducting narrative research with young people with learning difficulties: inarticulateness, unresponsiveness, and problems in presenting questions about time and frequency. Some of these issues were encountered in this research. Some children did not say much, their narrative was limited and they could not answer any complex questions, especially one boy. However avoiding open ended questions, understanding silences and non verbal cues, attending to what goes unsaid, distinguishing between expressive silences (waiting to be broken) and closed silences (waiting to be passed over) and picking up personal cues facilitated communication and helped the children express themselves (Booth & Booth, 1996).

Furthermore the interviews with children benefited from Morris's (2003) suggestion that it is better to always start with the assumption that a young person is at least capable of expressing preferences. With children with little or no speech it was

important that I found out in advance from those who knew that child about their preferred forms of communication and spent time with a child to learn how information can best be presented to him/her (Morris, 2003). For example one interview was conducted with a child who had a severe form of cerebral palsy and did not use speech to communicate, but was able to indicate what he liked and what he did not like. For example if asked something he did not like he would turn his head away. So I spent extra time with this child and also asked his mother to assist in interpreting his responses. This boy expressed the view that he loved going out and enjoyed the company of other children, liked watching snow fall and loved visitors, but that he did not like doctors.

Relating to a young girl in Bulgaria had the added challenge of a language barrier. Communicating with a child who has learning difficulties and limited use of speech through a translator required a somewhat different approach to that used with other children and it was decided that a significantly more flexible interpreting style was needed. Being familiar with the research and the questions enabled the interpreter to try and establish communication with the girl without immediately translating. When the girl's attention drifted onto playing with her toys the interpreter would translate what she had said. The whole encounter was audio recorded so later we were able to listen slowly and clarify misunderstandings. On the second encounter, outside of her therapist's room (in a local park) the girl was more interested in communicating and playing with me. Being able to speak basic Bulgarian helped, but also being outside created a more relaxed atmosphere for all of us.

### 3.3.3 FOCUS GROUPS WITH MOTHERS

Three focus groups were conducted with parents of disabled children and the organisation of these groups was supported by parents' associations in both countries. Even though efforts were made to include fathers, apart from one father in the focus group in Sofia-Bulgaria, it was only mothers who responded to the invitation. The importance of gaining trust in conducting successful interviews (Fontana & Frey, 2005) was experienced in all focus groups. Significant attention was devoted to introducing the project and myself, the reasons for doing the research, and the plans for using the data. Mangen (1999) highlights that respondents might exercise more caution when discussing sensitive issues with a foreign interviewer, and suggests organising interviews in familiar premises. Even though it might have been more of an issue in Bulgaria, all three focus groups were conducted on the premises of organisations parents were familiar with. Mothers in both focus groups in Bulgaria were positive and expressed willingness to share their experiences and views. The father in the focus group in Bulgaria was not so talkative and required more encouragement to participate.

Oakley's (2003) distinction between masculine and feminine paradigms was noted to an extent in all groups but especially in B&H, where the largest group, of eight mothers, was present. This focus group was more intense, loaded with tensions around trust, the researcher's intentions and background. The mothers kept asking questions about the research, about disability issues in the UK, and about my opinions. The issues we discussed related to social justice, human rights and it was not practical or helpful to feign indifference. They shared experiences of discrimination, frequent

humiliation and hardship and they clearly wanted to know if I was one of those who would further disempower them. Being a distant and formal researcher and not disclosing my opinions and views, was very hard at this stage and could have been interpreted as disrespectful towards the participants. I therefore opted for honesty and involvement, as advocated by feminist researchers (Oakley, 2003).

Towards the end of the focus group session the atmosphere became friendlier and mothers said they would like me to acknowledge their participation in the research and that they wanted to use it in their association for their advocacy activities. It was felt that mothers in this focus group wanted to draw me in and explore the potential for me to contribute to their agenda. This is in line with what Kamberelis and Dimitriadis (2005) indicate, when they advocate using focus groups not to extract information from participants, but also for imagining and enacting the emancipatory political possibilities of collective work. During this focus group we managed to reduce unproductive distance between us and to negotiate the interview process for mutual benefit as advocated by feminist researchers (Powell, 1996). This focus group corresponded to a feminist style of engagement, where sociological research is an essential way of giving the subjective situation of women a greater visibility, and interviewing women functions as a strategy for documenting women's own accounts of their lives (Oakley, 2003).

#### 3.3.4 INTERVIEWING ELITES

Interviews with high ranking officials often come under the umbrella of interviewing elites and it has been recognized that these interviews have special characteristics. In order to access a diversity of views about policy and practice, efforts were made to access government policy makers. All together six current government officials participated in the study. One interview was conducted with a former government policy maker, who was currently a university professor. According to Herod (1999) elites' organisations are more likely to produce large quantities of documents that can be useful as additional data, and can help in preparing research and verifying responses. However elite participants are less likely to share life experience and this was confirmed in this study. In relation to the sharing of documents only a few were provided, perhaps because relevant websites and means of official data collection are as yet not well developed.

Mangen (1999) considers the risks of cancellation, or an interview being conducted under pressure and with interruptions when interviewing experts and elites.

Cancellation was not encountered, but respondents in Bulgaria both verbally and non-verbally communicated how their time was precious and limited. They also retained an official stance throughout interview, communicating only official policy discourse.

Furthermore, elites in Bulgaria wanted to exercise control in arranging the interview setting and timing; being adamant that it be conducted in ministry premises, with their own translator and without a tape recorder. They explained that ministry protocol is to request official clearance for interview recording, however they agreed to note taking.

Whilst this corresponds to Sabot's (1999) claims that the reception given to foreign

researchers can function as some sort of public exercise, it does not correspond to the view enunciated by both Sabot (1999) and Herod (1999) that foreign researchers are not perceived as a threat, but as naïve outsiders who get granted access to important information.

A completely different picture was presented by the former Bulgarian policy maker interviewed who was informal and gave numerous examples of problems with policy making and EU relations. In the last few years Bulgarian child care practices have received extensive criticism and bad international publicity, created especially by foreign investigative journalists who have sometimes used covert methods. This might help to explain why current policy makers in Bulgaria exercised caution in dealing with a foreign researcher, as they may have been anxious to present a favourable picture of government policies and actions. These tensions were not noted during interviews with Bosnian policy makers, who were more flexible, less formal and prepared to abandon official policy lines in favour of critical reflection. This contrasts with the view that local researchers are perceived as a threat (Herod, 1999; Sabot, 1999). However Herod (1999) contends that positionality is messy on the ground with researchers emphasising different identities and roles according to the situation. It is hard to be conclusive on the extent to which my insider/outsider position, in relation to B&H and Bulgaria, played a part or whether the situation was more influenced by current mistrust of government policy makers. What it does show is that dichotomies of insider/outsider may not be sufficient enough to explain the behaviour of elites and that the current socio-political situation, the relationship with the international

community and the sensitivity of the issues under consideration are just as likely to play a part.

#### 3.3.5 FOUND IN TRANSLATION

Several authors have noted how little attention has been devoted to the role of interpreting and translation - either when considering methodology or when reviewing study findings (Twinn, 1997; Esposito, 2001; Temple & Edwards, 2002). This study involves, in all stages of the research, the use of three languages; English, Bosnian and Bulgarian and therefore working with an interpreter, as well as translation issues have necessarily been carefully considered. In Bulgaria some interviews were conducted in English with people who expressed a preference to speak in English with others conducted through an interpreter. In Bosnia interviews were conducted, transcribed and analysed in Bosnian, this being the first language of both participants and researcher.

It is argued that an interpreter can negatively influence communication and research outcomes if the interpreting issues are not properly addressed (Kapborg & Bertero, 2002). Davidson (2000) reports a situation where an interpreter created additional power issues or interpreted selectively, whilst Filep (2009) describes how interpreters may distort the original text and freely insert socio-cultural and generational commentary into the translation. To avoid such problems the interpreter was introduced to the study, aims, methodology, methods and terminology. We went together through the questions and possible ways to translate them appropriately into

the Bulgarian language. This was with the idea of developing a shared understanding of meanings. This was important because if we were arranging interviews by phone it was necessary that the interpreter was able to effectively communicate the research agenda and convince people to participate. Furthermore in planning the research we rehearsed what we would say about the study and reached the understanding that we wanted to make the interviews as informal as possible, and be aware of power issues, to give people a chance to talk and to respect their wishes regarding how the interview was to be carried out.

The interpreters' contribution continued after the interview, with them acting as a critical friend in discussing interpretations and reviewing interview dynamics, a process that can aid triangulation of the data. Temple (1997) argues that this approach allows for differences in understandings of words, concepts and worldviews across languages. In addition both interpreters (employed at different times) were local Bulgarians and good communicators which helped make the research less 'foreign' and closer to home for the communities we visited. According to Edwards (1998) the interpreters can be considered as 'key informants' rather than neutral conveyors of information. Discussions with the interpreters helped me reflect on meanings, enhanced my own understanding and led to increased accuracy of interpretation. This research confirmed Temple and Young's (2004, p.173) argument that translators always make a mark on the research and take on a role of analyst and '*cultural broker as much as a translator*'. Whilst working with the interpreters was at times challenging, it provided me with a gateway to Bulgarian culture and the people within it who do not speak English. As such it enabled me to engage with that culture more than if I had limited



myself to only English speaking Bulgarian participants. In addition there is a need to reflect on my own dual role - of researcher and translator - and consider issues arising from the translation of several key concepts in this study.

Shklarov (2007) argues that bilingual researchers need to negotiate, among other dualities, a dual perception of conceptual meanings. The bilingual researcher needs to achieve accuracy of conceptual understanding, in order to facilitate an adequate two way understanding. In this endeavour I discussed my translations and interpretations with several Bosnian friends who are fluent in both languages (Bosnian and English). These discussions sometimes challenged, though often deepened my own understanding. It is important to note in this context that Young and Ackerman (2001) regard discussion of the translation process as itself providing a check on the validity of interpretations. Language issues are paramount in disability research where language can be used to oppress disabled people and functions to maintain power relationships between disabled people and professionals – hence there are political issues as well as semantic ones (Oliver, 1994; Oliver & Barnes, 1998).

In the English speaking world proponents of the social model of disability use the term 'disability', which in Bosnia and Herzegovina is translated literally as '*disabilitet*'. However this word has nothing to do with the social model of disability. Instead '*disabilitet*' in Bosnia is a medical word, employed by medical doctors and not by disabled people themselves or organisations of disabled people. A more appropriate word in B&H right now is '*invalid*' and discursively closer to the English 'disability',

hence Bosnians say '*invalid*' for a disabled person and '*invaliditet*' for disability. Whilst invalid is considered an offensive and outdated word in English in B&H it is not seen as problematic, and is in fact preferred by disabled people's organisations since '*invalid*' in Bosnian carries no implicit negative cultural connotations. Discussion of the term and the discipline of defectology is provided in chapters two and six.

The same applies to the term '*handicap*', which in both American and British English is considered offensive because of its historical allusions to going 'cap in hand' when begging or seeking charity (Oliver & Barnes, 1998). The term is less frequently used in B&H now, simply because of the dominant role played by English language speakers who set the international disability agenda, where use of the term handicap has been largely discontinued. So, for Bosnians the words invalid and handicap are foreign words that had at some point in the past been borrowed from the English language, when those words were accepted in English speaking countries. Whilst this terminology, due to various social and cultural developments, has been changed in English speaking countries, its presence in Eastern Europe can be considered as a repository of this cultural memory even though the inhabitants there are entirely oblivious to this fact. English speaking people coming to Eastern Europe are aware of what they see as offensive language. However people who do not speak English have no overriding personal or cultural need to change these words because they have never carried the weight of cultural oppression which resides in their original usage in the English speaking world. Further discussion concerning the translation of '*exclusion*', a key concept in my study, is debated in chapter seven.

Acknowledging that the role of bilingual researchers is complex, Shkларov (2007, p. 537) concludes: *'The ability to perceive and consider the ambiguity of various linguistic, cultural, and ethical contexts is one of the essential conditions of achieving ethically sound research outcomes.'* In this respect Olher (2004) argues that translation should be studied as a discursive practice since the process incorporates the social, the cultural and the psychological in its domain. Translation then is not a product, but a process that involves negotiations of meanings, acknowledgment of discursive and social practices and understanding of different social frameworks. The ideas that presented the greatest difficulty for translation were the key concepts in my research, and these difficulties with translation were initially seen as an obstacle. However on reflection I realised that this constituted information and data in itself and provided yet further insight into how disability discourse and related concepts operate in one culture.

#### 3.3.6. ADDITIONAL METHODS AND STRATEGIES

Other methods used to complement interviews and focus groups were fieldwork notes and diary entries, document collection and the use of photographs taken on visits. As suggested by Walsh (2006) notes were taken as soon as possible after the event was observed and consisted of details of where the event occurred concrete descriptions of social processes, context and settings and whenever possible verbatim speech and descriptions of the interactions between people present. Some notes were taken immediately after interviews with a view to capturing the ambience and mood of those interviews and the quality of interaction. On other occasions notes were recorded after visiting institutions, special schools or family homes. These recorded the facts and

impressions of the environment and atmosphere. Early on these notes were wide and fairly unstructured, in time becoming more focused and relevant to emerging concepts and concerns, a process reported by Walsh (2006). Some of the notes reflected methodological and ethical dilemmas and cultural references. The atmosphere in residential institutions was particularly charged with emotion and participants' body language played a part in conveying messages. A sample of field diary notes can be seen in appendix five.

Prior (2004) comments that looking at documents is important not merely for their content but also for their function in human interactions and organisational settings; how they are produced, circulated and used. Various types of document were collected during the fieldwork e.g. brochures, copies of legal acts, guidelines, teaching curriculum, studies of disability policies, printouts of charts and statistics. The participants usually offered these freely and before long it became apparent, in line with Walsh (2006), what a valuable resource they were. During visits to residential care homes children's official records came up and it was clear that these records are important to staff - they proudly talked about how meticulously they were kept. Two families also presented documentation from hospitals, and details of assessments from disability commissions. They said that these papers have great value for them, since they are an official confirmation of the child's disability and a licence for receiving allowances. Other artefacts that were freely given were ornaments and cards made by disabled children and adults in occupational workshops. These are usually given to visitors as gifts or sold in charity auctions. A particularly rich insight into disability discourses was afforded by a music CD that contained popular songs by institution

residents. These revealed how disability discourses are reproduced in everyday life, as discussed in chapter five on residential care.

In addition a series of photographs were taken during visits to day centres, special schools and parents' organisations. As suggested by Bryman (2004), these photos were treated as data about the field, as an essential part of the field notes and a way of documenting the environment. These photographs revealed important aspects of people, the environment and the interaction between them. For example an interesting dynamic was captured between staff and residents during an institutional ceremony (discussed in chapter five). I made efforts to capture natural interactions, to avoid interfering by arranging people for a picture and to retain originality without retouching or removing details Flick (2002). Still, due to different levels of intentional or unintentional selectivity I am not using photographs as a factual window onto reality but as a reflexive account that examines with sensitivity and awareness my impact on what the photograph reveals (Pink, in Bryman, 2004 ).

### 3.4 DATA ANALYSIS AND VALIDITY

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In accordance with the approach of thematic analysis, the analysing occurred at the interim, later and final stages of the study without fixed boundaries between these (Miles & Huberman, 1994). This approach, involving the constant redesigning of analysis is present in grounded theory and is a familiar practice in qualitative research

(Glaser & Strauss, 1999). Initial data analysis followed a deductive style, analysing data according to predefined categories or themes, which were the broad topics covered in interviews: disability policies and practices, the influence of international actors, experiences of families and children, institutionalisation and deinstitutionalisation, and models of disability. This was organised separately for Bosnia & Herzegovina and Bulgaria to allow for cross-country comparison. Unlike quantitative studies, changes in interview protocol or the introduction of different modes of inquiry are both accepted and desirable, as they can increase internal validity and provide a better understanding of the research setting (Huberman & Miles, 1998). These adjustments were made throughout to allow for exploration of emerging concepts and themes, for example the notion of the double exclusion of families who live in rural areas. Furthermore the analytic procedure of thematic analysis was complemented and combined with strategies used by grounded theorists (e.g. Glaser & Strauss, 1999) such as looking into deviant cases and line by line reading of the text while also looking for processes, assumptions and metaphors (Ryan & Bernard, 2003; Seale, 2006).

Coding of themes was refined as the analysis reached deeper levels. Large numbers of codes were identified and these were treated as tags or labels for assigning units of meaning to the descriptive or inferential information attached to words, phrases, sentences or whole paragraphs (Miles & Huberman, 1994, p. 56). These were subsequently pulled out from the text then copied into a separate document with the identification tag that was related to a participant's name, and the exact place in the transcript, making later clarifications possible. Seale (2006b, p. 313) says that this

process can be understood as a type of indexing where sections of text are identified according to whether they contribute to an emerging theme. Efforts were made to both preserve the richness of codes - by keeping participants' original expressions - and to make these codes manageable (Ziebland & McPherson, 2006).

However it was apparent that these codes were not free from theoretical concepts as initially advocated by Glaser and Strauss, an idea which has been deemed a methodological myth on the grounds that abandoning conceptual networks would inevitably produce fragmented data (Kelle, 2004, p. 449). For example identified codes were frequently related to children's rights, and the social model of disability, whilst statements termed as exclusionary were also identified and treated as codes. These helped to organise the data, and identify general theoretical concepts and topics of interest. However, at the interpretive level careful reflection was needed to distinguish participants' concepts from my own, an issue which has been noted by Li and Seale (2007) who differentiated between constructs made by different actors in a social scene. They observed that as theoretical and conceptual frameworks were applied, these concepts frequently conflicted.

#### 3.4.1 WITHIN CASE AND CROSS-CASE ANALYSIS

The decision was made to favour cross case analysis as this strategy allows for comparisons to be made between different cases or groups composed of individuals from the same or different settings. The cases in this study were groups of individuals in different settings and circumstances but with key common characteristics, for

example, disabled children, parents, NGO workers, policy makers, staff in residential institutions, staff in community centres, and policy makers. Miles and Huberman (1994) argue that examining multiple actors in different settings enhances generalizability as processes, constructs, and explanation can be tested in several different configurations. However cross case analysis runs the risk of not recognizing variables within each individual case, as individuals that are grouped into cases are likely to have different characteristics. For this reason what was going on in each case was carefully considered. For example there were themes common for all mothers, but some issues were only identified by several and this is where teasing out specific variables became useful.

This deeper level of analysis was supported by a process referred to as 'OSOP' (one sheet of paper; Ziebland & McPherson, 2006) when all the different topics from coded extracts are presented each on a single sheet of paper (see appendix 6). With each extract aligned with the participant's code this visual presentation prepares the way for the next stage - axial coding – which involves a careful examination of these issues and a consideration of how they can be grouped into broader themes. The coding also involved looking for negative instances (deviant cases) that contradicted or supported the development of emerging theory (Seale, 2006). This included the responses of several professionals that did not fall under any particular category, or when their responses differed according to different variables. These instances were treated as significant because they added layers of explanation or introduced complexity to phenomenon which had previously been described uniformly. An example of this is openly negative talk about inclusion, which was encountered only in one setting.



Interpretation was enriched by respondent feedback (Ziebland & McPherson, 2006) and this strategy was used during and after data collections, as several respondents were willing to discuss interpretations either directly or through email correspondence. The analysis was additionally enhanced by an in-depth consideration of a few cases – one residential care home and close examination of each family (see chapter four). Interpretation was also deepened by using insights garnered from looking into ways participants use language to communicate their views and constructions about disabled children, as presented in chapter five.

#### 3.4.2 RESEARCH QUALITY, VALIDITY AND FEEDBACK

When it comes to examining the quality of qualitative research, there are two contrasting positions. One favours research that empowers, liberates and serves communities (see Denzin & Lincoln, 1998; Lincoln, 2002; Lincoln & Guba, 2003) - this is largely the premise behind emancipatory disability research. In the other camp are those who advocate for methodological rigour '*as a craft skill rather than realisation of philosophical or political goals*' (Seale, 2004, p. 381). For the latter group taking political goals as a foundation for research is problematic because there is no fixed consensus on the desirability of particular goals (Hammersley, 1995, in Seale 2004). However in disability research this position can be challenged because there is a general consensus that disabled children are discriminated against, suffer social and educational exclusion, and are more likely to be taken into care. Throughout this research the aim is to reconcile these positions - to use arguments from both to enhance the quality of

research. Stone and Priestley (1996) maintain that these two positions do not necessarily conflict. In fact seeking to achieve both goals is the obligation of the disability researcher.

A basic issue in assessing the validity of qualitative research is whether researchers' accounts are grounded in data from the field. I was therefore interested firstly in whether the presented versions are grounded in the constructions of participants and secondly how far these constructions are transparent to others (Flick, 2002). It is important to discuss the different perspectives of researcher and participants, since accepting only one perspective on reality will not increase understanding or move forward social change. Another dimension is catalytic validity, which is the degree to which the research process reorients focuses and energizes participants (Lather, 2003, p. 191). The extent to which this was achieved is hard to tell without following up participants and asking them about their experience. Nevertheless this dimension was noted in focus groups with mothers, who stated that they wanted to use the research results for their activities and advocacy. For example, discussing human rights produced a degree of self-determination among some participants. After one focus group mothers asked me to translate from English into Bosnian the Montreal Declaration on the Rights of People with Intellectual Disability so that they could use it debating with government policy makers. This I subsequently did.

In this research theoretical concepts of social exclusion and disability discourses were juxtaposed against the practices and experiences of children and parents, producing

new theoretical insights. This method was essential as disability practices and child rearing practices are socially constructed and dependent on cultural and local contexts, as debated in chapter one. For Taylor (1998, p. 277) the question of when to conclude a study is an arbitrary decision, but usually occurs when a researcher has gained an understanding of the setting or the slice of social life under study. It is when pieces of a puzzle come together, that insight and understanding are achieved. Taylor believes that this is similar to the idea of theoretical saturation used in grounded theory, although in the present study no confident claims of theoretical saturation are made as the topic is complex and further research is certainly needed.

The sampling strategies already discussed reflect Morse et al's (2002) approach with the careful use of purposeful and theoretical approaches and purposeful interviewing of participants who are relevant and knowledgeable of the topics under investigation. This ensured saturation of data, instead of saturation of participants, by bringing in new participants and perspectives, whilst returning to key participants to increase depth or address gaps in the analysis. Morse et al. (2002) contends that thinking theoretically and collecting and analysing data simultaneously or achieving an interaction between what is known and what one needs to know are key to achieving reliability and validity. This approach was followed in conducting pilot interviews and including new issues as a result, using different theoretical and conceptual frameworks to interpret the data, identifying themes, codes and issues all whilst data was being collected.

Triangulation is one of the most popular techniques used to demonstrate the trustworthiness of both data collection and results. It can utilise methods, investigators, theories, or data in order to compensate for one-sidedness (Steinke, 2004).

Triangulation is most used as a validation strategy though Denzin (1998) holds that triangulation is not a tool for validation, but an alternative to it. Triangulation was briefly mentioned earlier in this chapter in relation to methods and interpretation. To recap; the investigation relied on several methods: individual interviews, focus groups, field notes, photographs and documents as a means to broaden and deepen information. Comparing data generated from these methods initiated new insight, and aided reflection throughout, for example when interviews were triangulated with visual images.

In order to ensure validity; avoid reliance on one organisation and reduce bias in participant selection, I utilised several networks and approached different organisations for advice. Also during data analysis, codes and themes were checked with 'critical colleagues'-supervisors, interpreters, professional colleagues from B&H and Bulgaria. In terms of investigator triangulation, due to the nature of the research it was not possible to involve two investigators. However this role was in part fulfilled by the interpreters who helped in discussing interpretations of data and reflecting upon the interview situation.

In this chapter I have considered some specific methodological issues, ethical considerations, and aspects of the data analysis process, as well as the strategies that

have been used to achieve greater validity. Methodologically this study was approached from the position of the social model of disability and was informed by emancipatory disability research. In addition it has been aligned with views from the 'new sociology of childhood' with children treated as active social agents whose views and opinions are of significant worth. Furthermore the methodology used has allowed me not only to examine how policies affect the lives of children and parents, but also to discuss and uncover what are the key issues for practitioners and national policy makers. Finally the ethnographic elements of the study - spending prolonged time in B&H and Bulgaria, talking to diverse stakeholders, and carefully considering cultural and linguistic nuances - have enabled me to explore the hidden face as well as the lived reality of exclusion. This is discussed in the following chapters.

## CHAPTER 4

### FAMILIES AND SOCIAL EXCLUSION

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The previous three chapters have set out the theoretical framework, the social and political context in B&H and Bulgaria and the methodology for examining the social exclusion and inclusion of disabled children and their families. This chapter presents and analyses the parents' and children's views of their situation and the barriers to inclusion which they have experienced. Prioritizing what themes will be presented in relation to parents and children was a challenge, albeit a welcome one, owing primarily to the diversity of the families that took part in the research. This enabled a reasonably typical picture of the range of demands and challenges which families with disabled children face.

The parents differ in their educational level, the contexts in which they live, their financial status, whether they are employed or not and the extent to which they engage in activism around disability. In addition there are families where the parents enjoy a very strong marriage compared with those where the mother is unsupported, for example after the father had left following the birth of a disabled child. In spite of all these differences it was possible to discern a number of common themes, which were of crucial importance for a majority of the parents. These were: the negotiation of the child's disability from within the family; access to services and their use; and meeting family needs under a diverse set of circumstances. This chapter stresses the importance

in improving services, of taking into account the experiences of families and addressing social exclusion.

#### 4.1 NEGOTIATING A CHILD'S DISABILITY IN A FAMILY

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*'Every parent loves their child whether it's healthy or not' (Vesna, mother, B&H).*

The diversity of families affects how parents negotiate disability. From an analysis of the findings, it emerged strongly that taking care of a disabled child is seen and treated predominantly as a woman's job. The mothers also prioritized support provided by other family members, whilst both parents and children regarded relationships within the family and with friends as highly important. Even though no questions were directly asked about it, the mothers usually said something about the birth of their disabled child and their experiences of diagnosis. Their desire to speak about the birth and diagnosis indicates just what critical moments these are for parents.

The manner in which way parents are informed of their child's disability has frequently been identified as critical in literature (Graungaard & Skov, 2006; Clavering et al., 2006). For example Broster and Warner (2006) discuss the importance of disclosing information about a child's disability in an appropriate fashion, arguing the need for compulsory training in basic counselling and listening skills for professionals who work with parents. They refer to growing evidence that the way in which parents

are given the child's 'diagnosis' will affect not only how they adjust to the situation but also their subsequent treatment of the child. They propose that the information should be provided as soon as possible, in private and preferably with both parents and child present; it should be given by a consultant paediatrician and where possible a Health Visitor and/or a qualified nurse. The manner in which the 'diagnosis' and 'prognosis' are relayed should be sympathetic and caring, taking into account the emotional state of the parents.

When talking about their child's disability, the mothers frequently made reference to the faults of medical doctors. Some said that their child would be 'normal' if the doctors had not made mistakes or behaved negligently during birth, a theme that was also identified in the UNICEF (2005) study. In both B&H and Bulgaria parents frequently referred to the child's disability as the 'doctor's mistake', explaining that delivery was not performed up to standard and that the child did not get enough oxygen at birth. This issue might signal an ambivalent relationship to the child's disability as well as a lack of subsequent trust towards medical practitioners. This was exacerbated by the fact that sometimes children were misdiagnosed and parents had to take the child to different specialists:

*When he was six months old I took him to an eye doctor, because his eye was going to one side too much. The doctor said this would go away by itself. Then I took him to a neuro-psychiatrist, a neurologist, and a neuro-paediatrician. I just wanted the spasm to reduce, everything else would be easier (Azra, mother, B&H).*



The influence of the medical model of disability - the only one that is available to mothers in understanding their situation - was apparent in how mothers spoke about diagnosis - giving lots of medical details and information about physical symptoms. Nevena, a mother in Bulgaria asked me if I knew anything about the congenital impairment of her child. She still appeared confused about the diagnosis several years after her son had been diagnosed. This confirms Banach et al. (2010) arguments that families need support during time of diagnosis, as well as continued support and follow up services to help them adapt and meet the needs of their children. For some mothers the time of diagnosis was made all the more difficult because of poor communications with doctors. They appeared to be hurt by not being given a precise diagnosis straight away, interpreting this as carelessness or a lack of knowledge on the doctor's part:

*When my child was born, he slept a lot. I wondered why that was, but they told me that the child is just a quiet type. Then they said the child might be anaemic. After a few months we had the tests done and it came out that the child was not anaemic; I asked the doctor was everything alright, because the child had a strange head shape, and then he said it wasn't OK. I asked him why he didn't say straight away... It used to happen that he gets all blue when he cries. Nobody knew what it was, it later came out that those were epileptic seizures. How can it be that the doctors did not know what epileptic seizure looks like (Svetlana, mother, B&H)?*

During individual interviews mothers spoke about their feelings regarding the diagnosis and disability of their child. For example one mother in B&H talked about feelings of personal failure and inadequacy. The same mother said how she could not shake off the impression the medical doctors in the hospital gave her about her child:

*A whole group of them came to me soon after I gave birth. They said that something was wrong with the baby and that he will be handicapped forever. They were telling me what he will not be able to do. They treated me like a tragedy, but it was their fault, the*

*labour wasn't performed well.... I didn't want to tell my husband straight away...I let him be happy with the new baby. It was our first child, a baby boy, we wanted to be happy and all that. Than later I told him, but he never experienced it in the same way I did. Even though I have a good marriage, and a good husband and support in my family, in some things I was alone (Vesna, mother, B&H).*

This example shows how this mother negotiated emotions and care within a disablist society (Ryan & Runswick-Cole, 2008) coupled with a disempowering and tragedy discourse used by professionals. It also demonstrates that not only mothers whose husbands have left, but also those who are married, experience practical and psychological isolation in caring for a disabled child. Similar tales were recounted by several mothers.

#### 4.1.1. MOTHERS BEING ALONE

Priestley (2003) contends that it is generally the mother who provides physical care, accompanies the disabled children to public places and acts as an advocate for their equal rights, as well as being the child's confidante. Therefore Ryan and Runswick-Cole (2008) argue against 'gender blind' research that talks about parents in general, ignoring the fact that mothers of disabled children are more likely than any other mothers to take sole care of a child. A similar issue was evidenced in the present study, when from the outset, with the exception of one father, only mothers responded to invitations to participate in the research. It transpired that the mothers were primarily and frequently the sole carers of disabled children. Vesna, one mother who runs a centre for intellectually disabled persons in B&H had this to say: *'I often work with parents and I have met many single mothers. Fathers rarely come here. One of the reasons is because parents are inadequately prepared'*. Several mothers in Bulgaria corroborated this view outlining stories of fathers who had either left with scant explanation or who

had simply stopped calling (again an issue that emerged in the UNICEF, 2005 study).

In the *Centre for Autism* in Bulgaria, one parent, using her own experience of being a mother herself and of working with parents, reflected on these issues in a systematic way:

*The father mostly provides financial support. There are lots of families where the mother takes care of her children alone. When a child with a disability is born mostly mothers take care of the child and the fathers go to work. We also saw lots of situations where the father just leaves. He could still help but he just leaves. We have a large percentage of mothers who are taking care of the kids alone. By law, fathers have to continue to provide financial support, but just that. About 50% of the families are families with only a mother; mothers are taking care of the kids alone (Ana, mother, Bulgaria).*

According to Sloper and Beresford (2006) taking care of a child with a disability takes a major toll on parents' health and emotional well-being – something which was readily confirmed by the mothers in this study. In addition Ryan and Runswick-Cole (2008) argue that mothers of disabled children have a complex and contradictory position in disability literature because they are presented as either stricken by grief, loss and denial, or delusional if they portray a happy family life. Also they need to constantly prove they are acting in their child's best interest. Mothers talked of the stresses exacerbated by a host of challenges confronting them; the need for extensive care, negotiating therapies, contending with disability assessment commissions and fighting for fulfilment of their own and their children's social rights.

A common situation for most of the mothers was not only physical aloneness, but psychological isolation and lack of personal support. Apart from one instance where psychological support was given by a friend who happened to be a defectologist, most

parents said that though they have a consistent need for counselling, they never receive any. Most stressed that psychologists are people who need to be there before and after a diagnosis is disclosed. One mother expressed this in the following way:

*And we are not getting this at the time of diagnosis, somebody really needs to encourage you to go and fight for it and to do the best for your child; you need to know what is available, what kind of social support, like what services are there for the child, and for yourself to be able to understand how to take care of the child; because nobody trains you to be a parent and nobody trains you to be a parent of a special child and it is really a pity we don't have that. It is more important to have psychological support than financial' (Ana, mother, Bulgaria).*

Some mothers had no close relatives in their vicinity to help and no parents' association to provide any support. In the absence of community resources and psychological support provided by care workers, the other mothers mentioned support received from extended family members. To provide help with child care is the customary practice in Balkan countries, and this is how grandparents and relatives show their support (Todorova, 1997). However there are tensions around supporting a parent with a disabled child and this will be discussed in the next section.

#### 4.1.2 FAMILY MEMBERS: SUPPORT AND RELATIONSHIPS

During the course of this research it transpired that the presence of family ties and support was not always evident when it comes to caring for disabled children. One mother commented, quite resentfully, that the extended family had turned their backs on them after the birth of their disabled child. In addition several mothers argued that disabled children are treated differently and that grandparents and relatives do not feel equipped and are even scared to take responsibility for children, especially if they have complex needs:

*Maybe my family would help, but it is hard to accept care for the child if you don't understand what that child wants to say to you. His communication is by gestures. You need to spend half a year and 24 hours a day with him and to observe him, before you know how to communicate with him. He gets upset if he is not understood (Svetlana, mother, B&H).*

Mirfin-Veitch and Bray (2002) argue that literature on the role that grandparents play in the families of disabled children falls into two categories - those who do and those who do not provide practical and emotional support. In spite of the reluctance of relatives to help, still half of the mothers said that their parents did provide help with childcare. As Lidiya, a mother in Bulgaria reported, the support could be extensive:

*'...They engage with him very much. They go shopping, they watch television, they read books together and so on'.* One of the participants in this research was a grandmother who undertook sole responsibility for care of her disabled granddaughter. Another mother, in a focus group in B&H, mentioned the dedication of her father who is always in the school during break, to take care of his granddaughter.

Radka, the grandmother explained how she took complete care of her granddaughter. This appeared less a matter of choice for her, than of necessity, as her daughter had had to take employment abroad due to the lack of a suitable job in Bulgaria; this whilst the child's father had proven unreliable and left. Data suggested that whether grandparents do provide support depends on a number of factors - how close they live to the family, whether they accept the child's disability and of particular importance, the grandparents' state of health (Mirfin-Veitch & Bray, 2002). Several mothers endorsed this view - Milena, a mother in B&H expressed it as follows: *'Before, my*

*mother used to help, but she is withdrawing now, because she cannot anymore, she is getting very old'.*

Parents in this study reported that siblings, especially older children frequently take part in caring for their disabled brother or sister. The mothers however said that they cannot rely on older children to take on that responsibility permanently: *'My daughter still has not started university, so she has time to take care of him. I am worried what will happen once her lectures start, she will have no time...'* (Svetlana, mother, B&H). Another mother in the same focus group added: *'I have two girls and they help me with everything. They help their brother with everything, they are not embarrassed about it at all, and they don't take it as a burden'* (Zorica, mother, B&H). Indeed Heaton et al. (2005) argue that siblings must be considered in a holistic view of the family with a disabled child.

The parents agreed that siblings sometimes receive less attention, as parents focus on the disabled child. Additionally parents in B&H and Bulgaria said that some parents of a disabled child put undue pressure on their non-disabled sibling. They took the example of a mother who comes to their centre to illustrate this: *'She is pushing her daughter, who is a healthy child, to be the best student, to do sports and all that. Worst of all she doesn't let her spend time with her disabled brother'* (Vesna, mother, B&H). Indeed, the way disability influences relationships in a family and with the outside world was found to be important for both parents and children. Of note, however, the mothers in the focus groups in B&H and Bulgaria commented on how the disability of one child can positively influence non-disabled siblings, who may develop into more responsible

persons, better able to understand diversity and to challenge stereotypes about disability. Connors and Stalker (2003) in a UK context also found this to be the case in their study of disabled children and their siblings. Echoing this, Bernal (2006, p. 25) challenges assumptions that parenting a disabled child is all about persistent grief and instead argues that professionals need to be aware not only of difficulties, but also the positive aspects that come with having a disabled child as well as the adaptive capacities of families.

Strained relationships with parents were expressed by children living in institutional care (this is discussed further in chapter five), while children who lived with their family reported having warm and caring relationships with their mothers/carers, though the background to this was not always straightforward. An example of this is provided by the boy Mirza who was living with his foster mother. He kept stressing how happy he is to be living with her instead of in a children's home. On several occasions during the interview he made reference to how well he and his foster mother got along. However the manner in which he talked about their relationships carried the suggestion that he felt somewhat insecure as to whether she was happy enough to be living with him too: *'We get along very well, don't we? You are happy you got me, aren't you? I mean you could have got some awful child, somebody who will make problems'*. In another example Iva, who lives with her grandmother Radka has little contact with her mother now that she is working abroad:

*She does not cry for her mother any more. After she left, she came back on holiday, and then she left again, Iva was sitting at the table, and she was very sad, and then she scattered photos on the floor and she was looking at her mother in the photos and was*

*crying for her. But that has passed; sometimes she even does not want to speak to her on the phone (Radka, grandmother, Bulgaria).*

In analysing the responses of disabled children it was apparent that they do not often form satisfactory friendships with non-disabled children, something that was emphasised by their parents, four of whom reported incidences of bullying by non-disabled children. Sead, who lives in a remote village, very much enjoyed going to the Eid celebration, held in the nearby primary school, a few days before the interview. He had been delighted to spend time with other children and they had behaved well with him. However Sead does not have any friends. His uncle's children (maternal brother's), two young men are very good at playing with him, which I had the opportunity to witness, but apart from that he has no contact with other children.

Even though he had moved away, Mirza (now in foster care), continued to socialise with children from the orphanage where he had once lived. His foster mother explained that he prefers to be with the kids he knows, and that establishing relationships with new friends is not easy for him. The children, as well as the parents reported that non-disabled children and their parents do not visit disabled children at home. This is confirmed by Ytterhus et al. (2008) in a Norwegian study in which parents reported a lack of success in addressing loneliness and the social isolation of children with intellectual disability. In the focus group in B&H all mothers agreed with the sentiments expressed by Svetlana:

*In a healthy population children invite their friends home. When we have birthday parties for our children, we usually invite our friends. Healthy children and their*



*parents do not come to our birthdays. Those kind of friendships happen rarely or not at all (Svetlana, mother, B&H).*

Parents and children expressed considerable hurt and anger when describing encountering prejudice from people in public spaces. They referred to people staring at them out of curiosity or even straining to avoid looking at them. Such reports of disabled children being treated differently were common, as well as stories of children being bullied or avoided in mainstream schools. *The children from school somehow avoid playing with her... the teacher seems to have spoken to them, but somehow the society is not ready, probably it's the parents, some children don't want to play with her' (Radka, grandmother, Bulgaria).* This grandmother went on to say that there were a few children that behave well with Iva and help her in mainstream school and that despite the generally unfriendly social environment Iva was occasionally able to have fun. They had gone to a party recently where Iva was very happy dancing: *'She has a great sense of rhythm'.*

In a study conducted with parents of children with learning disability in Ireland, Kenny and McGilloway (2007) challenged the negative conceptualisation of the 'caregiver burden'. In spite of evidence of caregiver strain, participants reported positive and rewarding aspects to providing care for a child with learning disability. The parents in the study expressed satisfaction with their lives and had realistic expectations for their children and the future. Even though in B&H and Bulgaria parents reported love and strong bonds with their child and positive changes in siblings, the majority of parents did focus more on the negative aspects of their lives.

These were issues such as struggles with professionals, environmental barriers, lack of money, and negative public attitudes. However, it is important to say that they did not focus this negativity onto their children; it was the lack of appropriate support which they blamed and as such this justifies discussion of their experiences when accessing and using available support. These are the barriers to inclusion frequently mentioned by proponents of the social model of disability (Oliver & Barnes, 1998; Middleton, 1999; Reiser, 2001) and which are identified by those who utilise the social model when examining the situation of disabled children and their families (Dowling & Dolan, 2001).

It is possible that the parents in this study focused on the negative aspects as much as they did because they saw the research as an opportunity to communicate the difficult issues they face. Several mothers commented to me that this was the first time somebody had wanted to listen to them about their lives and the lives of their children; a striking illustration that researchers comprise part of the social field they are engaged in investigating. It also shows the failure of policy makers and professionals to recognise the importance of the parental perspective and expertise in providing enabling care (Goodley & Tregaskis, 2006) and improving services and providing outcomes for children.

This research confirms that the quality of life of disabled children and their parents is heavily dependent on how they interact with their environment, which of course includes the services available to them. Morris et al. (2009) argue that access to goods and services for families and children plays a significant role in exacerbating or mitigating social exclusion. This is true for all families, but particularly so for families with disabled children, since they are likely to use medical and social services more often, especially when the children concerned have complex needs (Preston, 2006). The parents in this study talked about a number of issues when accessing health and social care, not to mention education and the hardship of going through disability commissions. All mothers and carers in some way drew attention to the significance of relationships with practitioners.

Indeed, the significance of relationships between parents and practitioners has been reported widely (Kirk & Glendinning, 2002; Goodley & Tregaskis, 2006; Clavering, 2007). Similarly, in this study all the parents stressed that relationships with practitioners played an important role in their life. Medical doctors, social workers, teachers and disability commission members, amongst others, can help parents or make their experiences more difficult. The parents talked about situations where, for example, medical doctors did not know enough about a child's condition and did not advise the parents on how to approach the child. This was the case with a number of impairments but was particularly notable with autism. In terms of the parent-

professional relationship, this study confirmed arguments by Hodge and Runswick-Cole (2008, p. 645) that professionals continually act as experts, dismissing parents as over-emotional and ill informed, expecting them to carry out tasks set out by them, instead of being real partners.

Parents in the *Centre for Autism* in Bulgaria spoke of how little information was available to them when their children were growing up. As a result they had given up seeking advice from professionals and sought out information through their own devices - translating books themselves and learning how to work with their children. Parents in B&H likewise indicated that this was a problem for them, regardless of the impairment, with nobody telling them how to work with their child or what to expect. The following remarks from some of the mothers are typical: *'We have only a little bit of information about Down's syndrome; they say there is a literature, read on it...but doctors do not give me any detailed information'* (Milena, mother, B&H). Another mother commented *'the doctor didn't say anything to me; he talked something about more chromosomes, 47...I didn't understand that'* (Zorica, mother, B&H).

Mothers in both countries gave numerous accounts of adverse experiences with various service providers. The mothers in Bulgaria said that doctors are kind, but frequently unable to help them or do not help in the right way: *'the last doctor said, I couldn't do anything else. As for being kind – yes, they were kind. They tried to help as much as they could'* (Snezhana, mother, Bulgaria). Another mother in Bulgaria remarked that a doctor's intervention with sedatives had seriously affected her son in that: *'he became*

*agitated, started hitting his head, otherwise he is healthy, and he has given him such medication'*  
(Rosa, mother, Bulgaria).

The mothers in B&H reported negative experiences with practitioners more often and apart from a few isolated examples it appeared that medical practitioners, especially GPs, had little understanding of the situations facing disabled children and their parents. Traditionally in B&H people go to see their GP's early in the morning and if the surgery is busy they wait, sometimes for several hours. This system is undergoing reform, with the introduction of family medicine and an appointment making system, but meanwhile the following is not uncommon:

*One time I took my child to a doctor, and a nurse said to me 'Come tomorrow at 7am and take a number'; but I could not have been there at 7am, especially I would not have been able to wait there with the child in my arms to be seen. I wonder if there is any way we could be issued some kind of certificate that would help us go through services with less stress...I have had enough of explaining (Svetlana, mother, B&H).*

A rare positive experience was given by Azra, a mother in a remote village in B&H. She said how much it meant to her when the director of the hospital in Sarajevo went out of his way to help make her son's operation be a less traumatic experience. On the other hand her experience with social workers and the disability assessment commission were not so positive. Azra said that social workers came only once to her house, but did not want to come inside to see Sead, instead they just sat outside for a short while and left. Another major problem with social workers occurred when they discontinued her valuable support of 25 Euros, stating that she must go out and work. When Azra protested that there were no jobs in the village and that nobody could take care of Sead, the same social worker told her: *'Get yourself a maid and she can take care of*

*him while you go to work. We are not Germany to give you so much money'. Azra*

complained to the Federal Ministry of Social Welfare and won the appeal, however she has yet to receive her money and has never had an apology for this behaviour.

The parents in B&H complained especially about the bureaucratic approach of social workers. There are many papers to fill, whilst families have to wait months before they learn of decisions about entitlements. Mothers in B&H reported examples where social work centres had lost their documentation, which meant they had to go about collecting papers and medical certificates all over again. In addition several mothers spoke about the inconsistent practices of social workers and the different treatments they receive. One mother complained how social workers had given free nappies to another woman who was in the same situation as herself, but had sent her a letter refusing her any entitlement to them as "they are not on the list of orthopaedic aids". This is an example of how unfair 'discretionary practice' - not based on a 'rights' model – can be. Entitlements and financial support was therefore another significant and highly problematic theme.

#### 4.2.1 FINANCIAL SUPPORT AND ENTITLEMENTS FOR FAMILIES

Reviewing the situation in the United Kingdom, Sloper and Beresford (2006) contend that the social and financial needs of a family with a disabled child frequently go unmet, and that they are more likely (55%) to live in poverty, and to suffer higher levels of stress and lower levels of well being compared to parents of non disabled children. This situation is further exacerbated in countries where the income is lower

and there are fewer opportunities for support (Kulagina, 2003; UNICEF, 2005) as is the case with B&H and Bulgaria. In addition, and as confirmed by parents, the costs of caring for a disabled child are higher. For example the parents in B&H and Bulgaria were keen to try out different therapies, massages, special spas, exercises and operations. Some of these therapies are free, while parents paid for some themselves, creating an additional burden to their already stretched finances.

In reviewing the impact of the Disability Living Allowance (DLA) in the UK, Preston (2006) argues that additional financial support does make a real difference to families' lives, that increases in income do reduce stress levels, whilst simultaneously enabling families and their children to be more active participants in society. Preston (2006) further argues that the DLA and associated benefits need to be more reliable sources of income for parents/carers who combine working with caring for their disabled children. The government of the Federation of B&H has taken up this approach, but neither the other entity of the Bosnian state, Republika Srpska, nor the government of Bulgaria have. Bulgarian government policy makers, when interviewed, argued that increasing financial benefits only creates dependency and further reduces the chances for parents to participate in mainstream society. However, all the parents that participated in the Bulgarian focus groups claimed that any increased financial benefits would be highly desirable in meeting the additional costs incurred in caring for a disabled child.

Parents in Bulgaria said that entitlement for personal assistance and reduced or free transport costs are financial benefits that they find useful. Still, around one third of parents either did not seek financial support from the state or else did not know that assistance was available, usually because nobody had informed them. Parents in B&H further commented that there needs to be someone who will tell them about their entitlements and rights. In B&H parents of disabled children have a legal right to work half time and receive a full salary from their employer. However only one parent in the focus group in B&H said she had used her right and that was because she works in a government institution. In a time of high unemployment and fierce market competition, the parents commented that they do not feel confident to use this right if an employer is a private firm. One mother, who was facing these issues directly at the time she took part in the group, explained:

*I didn't use privileged working hours and I worked from 7 to 4, then my girl got ill. I worked in a shoe factory and they told me not to come any more, they gave me back my papers, even though they said they couldn't sack me. I still don't know what the outcome will be (Jelena, mother, B&H).*

Some new policies are simply not well designed to meet the needs of parents. As an example, parents in Bulgaria can be compensated within a programme of personal assistance but if they are, they then lose their right to work all together. The mothers in Bulgaria explained that the personal assistance scheme is intended solely for people who do not work and have no other income. They said that the extra care parents need to provide cannot be considered under the scheme as long as a parent has any other income. This according to the mothers is unfair: *'I can work during the night, as I do now. I am with him during the day'* (Rosa, mother, Bulgaria). The personal assistance fee



however is too small as it is and cannot replace employment: *'I receive 157 BG lev (70 pounds) for looking after him, but now I have no right to work. If I work this money will be stopped'* (Snezhana, mother, Bulgaria).

Overstretched finances and having to give up jobs due to care demands are international issues facing families with disabled children (Sharma, 2002; Clarke, 2006). This situation can lead families into poverty, which is strongly associated with social exclusion, as argued in chapter one. Figure 1 in chapter one also shows that accessing services and having equal opportunities is a prerequisite in taking inclusion forward, but to what extent these issues are being addressed is debated in the next section.

#### 4.2.2 ACCESSING AND USING SERVICES

In spite of having a policy which is supposedly oriented to increasing social inclusion and fulfilling children's rights, the parents gave numerous examples of how this is not happening, and how they experience discrimination when trying to access services available to non disabled children. As mentioned in chapter two, policies in B&H and Bulgaria now guarantee the right to education for every child, but as the parents indicated, when it comes to disabled children, and children with complex needs in particular, this right is not always fulfilled. The mother of one child with cerebral palsy in B&H appeared very puzzled when asked whether she had tried to enrol her son into the village school. She had, she said, not even thought about sending him to the school and couldn't see how it could be possible. Nobody had mentioned that possibility to her even though she has been in contact with numerous professionals in health and social care. This boy is very happy when around other children and with

some adaptation a local school would be able to accommodate to his disability. Sadly nobody has so far taken any steps in that direction.

The Bulgarian parents of children with autism spoke of very bad experiences with accessing education. In their view children's needs are not met in special schools, while mainstream schools are unprepared to work with their children: *'we tried ordinary schools and different day centres, but these children are not wanted in most of the places because they are hyperactive'* (Lidiya, mother, Bulgaria). Several parents took the decision to withdraw their children from school all together, even though they were aware of the right to education, and are themselves very well educated:

*You can explain about children's rights, they can understand about children's rights, you can show every single document on that...they would say fine, good, but they will make me feel like my child is not benefiting from this kind of education and that he will get worse if he stays in a hostile environment, rather than receiving warm, attentive treatment. That's a really tough decision. I had to answer to the child protection agency why I had kept my son out of school (Ana, mother, Bulgaria).*

There were some parents who said that they had sent their children to mainstream school in the hope that they will behave like 'healthy children'. Others had done so because they did not want to separate the child from the family by sending him/her to a special school. Policies in both B&H and Bulgaria now give parents the choice of whether their child will go to a mainstream or a special school, but having a policy does not mean that it will be implemented. This was discussed by parents in Bulgaria who are convinced that integration is not working well:

*Now it is really harder for the schools and for teachers to refuse those children to go to school and it's really hard to integrate them fully...they still give teachers in mainstream school a hard time, so the teachers are pushing the parents to withdraw the kids from the school (Tatyana, mother, Bulgaria).*

In this study a number of problems have been reported (in both B&H and Bulgaria) with the work of the disability assessment commission, a body which occupies a pivotal role in accessing social care or educational support. If a child has not been assessed by the commission and given a special needs statement or disability classification (expressed as a disability percentage), then parents are unable to claim social support, free medical aid, mobility aids, or request support in mainstream classes. Parents of children with intellectual disabilities in B&H say that they are frequently given the message that it is difficult to give a disability percentage for children with intellectual disabilities if they do not have any obvious physical impairment. They are thus classified with a lower disability percentage and therefore receive reduced welfare entitlements. The parents in B&H reported finding the disability assessment experience extremely stressful and were adamant that the children do not like going before the commission board, something over which they are given no choice. As one mother bluntly put it '*Well what can you do, there is no support without categorisation?*' Runswick-Cole (2007) also reports similar issues in the UK where the Special Educational Needs and Disability Tribunal process is experienced as stressful and demanding for parents and children.

Professionals also expressed dissatisfaction with the disability assessment commission. The fact that the children are taken before a panel of professionals and all the

diagnostic procedures carried out in the space of a single day, with no allowance made for the emotional state of the child, was behind this discontent. There is recognition that the process has to be made less stressful for children and parents, with decisions reviewed periodically. The mothers reported they have to go before the commission and pay for this service if they want to claim another benefit, even though the commission simply copies the same findings from one document to another, without examination or monitoring of the child's progress. Similarly, mothers in the focus group in Bulgaria reported having to renew their disability assessment results every three years. They too were dissatisfied with the work of the commissions and reported finding the whole experience hurtful, as reflected in the following comments of one mother: *'There are two or three medical examiners who ask him some questions and they say how damaged he is...and then on the basis of this he receives a percentage, on the basis of how damaged he is' (Lidiya, mother, Bulgaria).*

Accessing and using health care in both countries was not without problems and numerous instances were reported of disabled children being refused care or given substandard care. Dental care is especially problematic. Most dentists in B&H and Bulgaria refuse to treat a child with an intellectual disability or epilepsy. In addition mothers report situations where medical staff did not know how to approach their children. Such insensitivities as giving parents an ad hoc diagnosis, accusing them of neglecting their child or blaming them when their child fell ill, were also reported during the focus group interview. One mother reported being made to wait for seven hours in a hospital corridor before she was seen by somebody.

### 4.3 MOVING TOWARDS SOCIAL INCLUSION OF DISABLED CHILDREN AND THEIR FAMILIES

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As argued in chapter one, social exclusion is related to inequality and lack of opportunity, and these experiences are common for both the parents of disabled children and the children themselves. This picture is repeated by the findings of the current research and confirms Dowling and Dolan's (2001) view, that when applying the social model of disability we can see that barriers in society relate to the entire family and not just the disabled child. This of course adds weight to the argument that support needs to be geared to the family as a whole. Support is especially critical for families who are unable to meet the costs of caring for a disabled child. However, a system of comprehensive financial support, community resources and provision of relevant and timely information are either insufficient or completely lacking in both B&H and Bulgaria, a fact confirmed by parents, and professionals alike.

Parents had a number of suggestions to make with regards to how the present situation can be improved. The mothers in the focus group in B&H praised a new preschool for children with special needs: *'In Banja Luka we have a special preschool for these children and that is a real asset for the town. You have some kind of safety when your child is there'* (Jelena, mother, B&H). In addition numerous suggestions were put forward for how parents' organisations can be strengthened to provide community support for them and their children. Parents who accessed community day centres testified to what a great difference this service had made to their lives. Financial

support also featured high on the priority list for parents, as well as the need to improve services and to educate service providers about different impairments. This would allow the children to benefit from local community services instead of having to attend specialised clinics and special schools. All parents agreed that support is required from the outset. One mother in Bulgaria envisaged how such a support system might work, both logistically and practically.

*Support for parents can be a policy here. By supporting parents to stay together you actually support the child. When a child gets a diagnosis somebody or a team needs to start working with that child whilst another team can start working with the parents to stay together as a family; but at the same time parents can be trained how to work with this particular child and how to approach his/her disability (Ana, mother, Bulgaria).*

The expressed need for such a support system transcended the occupational, educational or financial status of the parents. All parents reported this is what they desire and need, whatever differences they may have. The academic literature shows cognisance of the considerable complexity and diversity which exists among families of disabled children (Carpenter & Carpenter, 2002) something which was well captured in this study. The differing circumstances in which families live, highlights the need for individually tailored packages of care to meet both common and individual needs; it also indicates that care packages must be directed toward the social inclusion of these families. The examples given in the next section show that services need to be able to respond to the complexity of families with disabled children.

This research identified numerous examples of mothers fighting for their children's rights, for increased financial support, dealing with professionals and trying to improve service provision. Ryan and Runswick-Cole (2009) argue that mothers of disabled children advocate more frequently and with more complexity than mothers with non-disabled children. Furthermore they argue that mothers often take on the role of activist, even though they do not always identify themselves as such. The same has been found in this research identifying numerous instances of mothers advocating on the levels of service provisions and policy. In addition, chapter six shows how mothers of disabled children in B&H and Bulgaria organised service provisions previously missing in the community. However the role of mothers and parents as activists is unrecognised.

#### 4.3.1 MEETING THE NEEDS OF DIVERSE FAMILIES- SOME CASE STUDIES

One of the families visited during this research comprised a single mother, Azra, living with her severely disabled son Sead in a rural village in Bosnia and Herzegovina. The trip there, in icy, wintry conditions, was thought provoking and brought home to me how remote and difficult a place this is to access. This is especially so during the winter period when Bosnia is covered in snow for months on end. The bitterly cold conditions made the village seem even more isolated and remote. No people were around and only two cars and an old mini -bus passed by on the way. At the centre of the village was a small mosque, a grocery store and a betting shop. When I asked for Azra and Sead's house a young man outside the shop said: *'Is it that woman with that child, that immobile boy'?*

### Case study 1. Sead and his mother Azra

Sead is 13 years old and has a severe form of cerebral palsy. He does not use speech to communicate, but Azra says he is perfectly able to indicate his preferences and wishes. They live in Azra's brother's house which has not been made physically accessible for a child in a wheelchair. Azra's husband left when she gave birth to Sead and has never made contact since. It did not look like she wanted to elaborate on this topic; it seemed that she wanted to talk about Sead and not so much about herself. She spoke about the practicalities of taking Sead to different therapies. He needs spa treatments, speech therapy and defectology treatment, though these services are not available in the village. To reach the nearest town where some of the services are provided they must travel for 25 kilometres in a small and difficult to access bus: '*...it was not too bad when he was smaller, but he is heavy now and it is increasingly hard for me to manage*'. Sead never received a wheelchair or any mobility aids from social services and so he uses an old, rusty, oversized wheelchair that once belonged to an old man in the village who died. As a single mother, who has suffered tragic circumstances in her extended family Azra takes care of Sead all by herself on very limited finances. Her chances of employment in the village are non-existent which means they cannot afford to move to a bigger city and pay for rented accommodation. Azra is however very much looking forward to a relatively large increase in disability allowance brought about by the 2006 amendments to the law governing social welfare in B&H. She said this money would make a great difference to her life and make her finances manageable.



This case shows, and NGO workers in B&H and Bulgaria have confirmed this, that levels of social exclusion are usually much higher when disabled children and their families live in remote villages. Distances from towns and services, parents' poverty and impoverished environments further exacerbate social exclusion. Furthermore community day centres are not built in small villages. A community day centre and rehabilitation centre was, in fact, exactly what Azra needed, but they were not reachable. Another option would have been an outreach service whereby a defectologist or social worker could visit regularly to work with Sead. Furthermore a local school needs to be encouraged to include Sead in the education process, instead of keeping him excluded from other children in the village.

The needs of another family encountered in B&H were much better met - this foster family enjoyed far more positive experiences. As previously discussed in chapter two, fostering is not well developed in Bulgaria, but in B&H is gaining increasing attention and popularity. Even though foster parents are unlikely to take on disabled children in B&H (UNICEF, 2003) there are exceptions and this study includes one foster family as shown in the next box 4.2.

#### Box 4.2 Case study 2- Foster family Saliha and Mirza

The woman, Saliha who is in her early sixties and retired, said that she became interested in fostering some 6-7 years ago when her husband died and two of her children left home. She started to care for fourteen-year-old Mirza last year, who, following the tragic death of his parents spent time in a psychiatric hospital and an orphanage. Whilst in the orphanage his situation deteriorated and he developed learning difficulties and emotional problems. It was a defectologist in the hospital who suggested a foster care placement for him. Since being in foster care his emotional problems have subsided, whilst his learning and educational outcomes have improved dramatically. Saliha says she receives sufficient support and money for raising Mirza: *'They visit me every month, either from the centre for social work or from organisations (an NGO that works on fostering), they are all connected. Every last Thursday in the month we have a meeting in the organisation...'* In addition Saliha reported that foster carers are trained to provide parenting to children and are supported in times of hardship, something that biological parents said they were missing. She said that training provided by the NGO promoting and supporting fostering in B&H was very useful to her. Both Saliha and Mirza talked positively about their experiences. Their example shows that the needs of diverse families can be met with timely and carefully tailored interventions.

As previously indicated, family policies and attitudes towards disability have shifted with the transition from communism to democracy. These changes were reflected upon by one family who have experience in using services for disabled children in both systems. Anuska is a disabled Bulgarian woman, an activist and a poet. She is now in her thirties and has complex needs and lives with her family in the suburbs of Sofia. When Anuska was growing up in communist Bulgaria the schools were completely inaccessible, hence she had to give up formal schooling at the primary school level. Her

parents had no support from the state and her mother worked full time, with the family having to pay for Anuska's extra care themselves. Now Anuska has a personal assistant under a new municipality scheme. She and her family said that things were markedly different now - disabled people are more visible and there were various initiatives, aimed at improving social inclusion, being launched in Bulgaria.

Unfortunately their experience is that these initiatives are often not sustained or do not reach all the people who need them. For example accessible transport is still limited, whilst rehabilitation and appropriate medical care are not fully available. Anuska said that she experiences numerous barriers in participating in mainstream society. This was confirmed by another Bulgarian family, as presented in case study 3.

#### **Box 4.3- Case study 3: Iva and grandparents**

A family interviewed in Bulgaria was one where the grandparents took care of a nine year old girl, Iva, who has Down's syndrome. The grandparents were reluctant to take on the responsibility, but Iva's father had left the family, and her mother was not receiving any state help. Due to the lack of employment opportunities in Bulgaria Iva's mother decided to leave her with her grandparents and to go to work on a foreign owned ship, a job that does not allow her to come home and visit her daughter often. However she is now able to provide financially for Iva, herself, and her parents. The grandmother Radka spoke of numerous problems in her efforts to access services and take appropriate care of Iva. Due to the lack of opportunities for schooling and no day centres in the town where they lived they had moved house and came to live in Sofia, which the grandparents found difficult to deal with. Even though they feel that life in Sofia offers more opportunities, there are certain barriers in using services. For instance it has still not been decided whether the grandparents can be registered as personal assistants. Furthermore they have not yet been allowed to use day centres, and will be able to only if they adopt Iva or if the mother gives them authorisation. For them the day centre is especially important in summer during the school break.

As with the case of Sead, the example of this grandparent's family shows that services are inflexible towards the needs of diverse families.

#### 4.3.2 CHILDREN'S RIGHTS-PARENTS' WISHES-PRACTITIONERS' DECISIONS

Apart from an adequate standard of living, disabled children also value education, a nurturing environment and participation and involvement in decisions that affect their lives (Middleton 1999; Morris, 2001). These are dimensions in addition to the rights enshrined in the UNCRC (1989) that can increase the social inclusion of disabled children. However, as seen throughout this chapter these rights, even though seen as a vehicle for inclusion (see chapter one), are all too frequently violated for disabled children. During the research it became manifestly clear that children's choices in both B&H and Bulgaria are severely restricted by disabling social structures. The boy who lives in a rural area likes being with other children and likes going out, but more often than not spends his days at home, in one room with his mother. Nobody ever suggested enrolling him in a mainstream school, whilst trips outside the house are difficult not least because the house where he lives is inaccessible and he lacks an appropriate wheelchair.

Parents gave many examples of children being discriminated against - in education, by medical doctors and in not having friends. Even when children stay with their families they often live in poverty, miss out on education and are prevented from using community services because of numerous structural barriers, and societal prejudices. Poor standards of living, lack of day centres and inclusive educational opportunities

were seen as problematic by both children and parents. These issues are recognised as problematic by policy makers and attempts are being made to advance inclusion through the opening of day centres and by improving access to mainstream schools for disabled children.

However, this research demonstrates that disabled children's right to participate is not being adequately addressed in policy making. The right to participate, be consulted and supported to make choices has not been prioritised either by professionals or parents, even though there is abundant evidence (see chapter one) to suggest that children's participation is central to social inclusion (Hill et al., 2004). For example, both professionals and parents usually spoke about parents' wishes when considering inclusive or special educational options. However there were instances when the wishes of parents were apparently taken into consideration, but behind this it was professionals who made the actual decisions or convinced parents that a particular option would be best. Apart from occasions when parents engage in activism and form an association themselves, it is professionals and policy makers who develop laws and decide what they consider is best for the child. In the struggle between parents and professionals concerning what is best for children, nobody is asking the children and this is especially true where children with severe disabilities and communication impairments are concerned.

It seems that Mirza, the boy now living in a foster family, was given more opportunities to make choices once he left the orphanage. He talked about what he

wants to do when he grows up, what he likes to do now and how he chooses his friends. In an interview he said that the children's home reminded him of an army barracks, with too many children, unreasonable routines, and uncaring staff who sometimes used physical punishment. Of his foster home Mirza said: *'I am so happy here, as if I was born here. I have my privacy here... I passed this year with very good grades in school, it was impossible before... You know, for me this house is like heaven'*. There are a number of reasons why it is that he has more opportunities to make choices now that he has left state care. His foster parent is trained by a forward thinking NGO that addresses children's rights; he lives in the city; he does not need mobility or communication aids and he was fortunate to come across professionals who suggested inclusive options for him. The path he has taken has proven to be a good one for him, but again it was professionals who were deciding what is good for him.

#### 4.3.3 UNMET NEEDS AND UNHEARD VOICES

The concept that a child's disability of necessity causes distress, crisis and pathology is gradually being superseded in Western societies by an understanding that families with disabled children have a variety of possible responses to their situation (Bernal, 2006). These views informed this research and during interviews care was taken not to impose models of individual pathology or tragedy. Unfortunately parents in Eastern Europe are only just beginning to experience the possibilities provided by support and alternative visions of disability in society. This is no doubt why their stories are so dominated by frustration and disappointment. Even though none of the parents presented their life as a tragedy, they often steered discussion into talking about the hardships and difficulties they face in conducting their usual activities.

In spite of unmet needs all parents were adamant that they would never place their children in state care. All the mothers continued to stress how much they love their children and that they will never give them up, as long as they can care for them. More than half of the mothers, did however, express concern about what will happen once they are no longer able to take care of their disabled children themselves: *'Now I am 60; I am divorced; if I die I don't know what will happen to him. There should be protected houses...with a little care he can manage'* (Snezhana, mother, Bulgaria). This is in line with Grant and Ramcharan (2001) who argue that families apart from 'caring for' express 'caring about' which is emotional labour and worry for the child with intellectual disability.

Some of the parents in this study had had to move house so that their child would be able to use community resources in bigger cities, rather than going into residential care. Others went to great lengths to ensure not only that education and professional support was available for their child, but also that the child would remain with the family:

*We used kindergarten from Monday to Friday, so we would take him there in the morning and take him back in the afternoon. Sometimes there would be a big snowfall, but we would still take him back home, because at home he has his own bed, his parents, his sister* (Rosa, mother, Bulgaria).

When parents were asked whether institutionalisation had been suggested to them by professionals, 7 out of the 23 parents who took part said that it had, but that they had refused. Institutionalisation was more often suggested in Bulgaria than in B&H,

especially where the child had a severe disability. One mother in Bulgaria said that professionals suggested institutionalisation straight away, trying to convince her by exhortations that: *'everything is free; it will be convenient for you'*. The suggestions were usually made without too much persisting. However Tatyana, a mother in Bulgaria, who was 42 years of age and unmarried when she had her son, had a very different experience immediately after the birth of her son:

*When I was in the hospital they came to me 2 or 3 times asking me whether I was thinking of leaving the child, because I was 42, a single mother, no husband. Every time I had to explain that at this age I was able to make an informed decision whether to have an abortion or to keep the child, and as I decided to keep the child, there was no point asking me now whether I want to leave him in the hospital for somebody to adopt. I said to them, in the hospital office, to get in touch with each other and to understand my position that I will not leave the child and to stop harassing me with that...*

It is to be expected that in recent years, with pressures from the EU and human rights approaches, attitudes may have changed. Indeed, social workers in B&H stressed that institutionalisation of a disabled child is absolutely the last option for them. In interviews with staff in residential institution in B&H they said that in the last few years they had hardly received any requests for admitting a child. However, reports from Bulgaria on abandonment were mixed, so that while some professionals and policy makers said that the number of children in institutions had been reduced, there were others who claimed that children are still being institutionalised.

Institutionalisation, it should be remembered, does not only happen to disabled children, but also to Roma children and children born to young single mothers, as illustrated by one Bulgarian informant:



*Some babies are just left in the yard of institutions, while some were abandoned after the first year; actually this is a new phenomenon; first of all we have girls who get pregnant between the age of 14-19, so we have 10,500 babies out of 17,000 babies in 2005, borne by these girls. We have these girls who either abandon their children right away, or they try to take care of their child for a year, because they receive some kind of payments, but when that ends they leave their child in a baby home (International NGO worker, Bulgaria).*

This chapter has presented and analysed the voices of parents and children in B&H and Bulgaria and uncovered what they identify as barriers and obstacles for inclusion. The parents valued participating in the research and reported seeing it as an opportunity to communicate their experiences and practices as well as the effects of policy. The views of disabled children and their parents are rarely acknowledged in policy making in B&H and Bulgaria, even though their voices are crucial in identifying what makes services effective and workable for them as opposed to what works for professionals (Beresford et al., 2003). The parents reported numerous issues in accessing education, health care and community services. It emerged quite strongly that as families they frequently felt discriminated against and excluded, thus supporting the position that the exclusion of disabled children needs to be addressed in a family context. The parents argued that increased financial support, as well as provision for early childhood care and education, is vital if inclusion is to be realised.

Obstacles to inclusion have been identified in the work of professionals who frequently see impairment without any regard for children's needs or rights. As identified in this research the relationship between parents and professionals is an area where significant improvements are needed. This chapter has also shown that the diversity of

families is something which has not been addressed sufficiently in policy and practice. Parents in rural areas for example, have even less access to services than their counterparts in cities. In spite of the challenges they faced all the parents that took part in this research decided to raise their child in a family environment. However, unmet needs and lack of support are the main reasons why parents in Eastern Europe do place their children in residential care - sometimes this has been the only option (UNICEF, 2005). Institutional care remains a hotly debated issue in Eastern Europe – both because of its quality and its prevalence. This is a debate which is loaded with emotional and political significance. The next chapter then turns to the question of residential care – as one which is significant in exclusion/inclusion debates in B&H and Bulgaria. The voices of those from inside institutions – both children and staff - most often go unheard. The next chapter includes these voices in the debate on residential care in Eastern Europe.

## CHAPTER 5

### INSTITUTIONAL CARE OF DISABLED CHILDREN

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This chapter focuses on residential institutions and residential special schools in Bosnia & Herzegovina (B&H) and Bulgaria. These establishments are frequently seen as a major obstacle to the social inclusion of disabled children. Once a child is placed in residential care, family and community ties are usually broken and the life of that child is confined to that institution's walls. In order to contribute to an ongoing debate on the topic this chapter will examine this complex issue in more depth, starting by outlining the main characteristics of institutional care. The two sections that follow will examine the institutional discourses, constructions of disabled childhood and life in residential care from the perspectives of staff and children. The final part debates deinstitutionalization strategies and the obstacles to it and outlines possibilities for transforming residential institutions.

#### 5.1 CHARACTERISTICS OF INSTITUTIONAL CARE IN B&H AND BULGARIA

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In B&H residential institutions are places where disabled children or adults live, receive rehabilitation and attend occupational workshops. In the Bosnian language these places are called '*zavod*', which means institute and signifies a scientific orientation. In Bulgaria however, residential institutions for children are more frequently called children's homes or social homes, thus stressing housing and a

protection component in its approach. In this thesis residential special schools are also considered as a form of institutional care, even though they are different from permanent residential institutions. The major difference is that children living in residential special schools usually keep contact with their families and go home for holiday, school breaks, or weekends. However different in their physical structure and in the purpose they serve, all residential places in this research have, to varying degrees, some similarities and resemble a number of Goffman's (1961) characteristics of total institutions. The crucial similarity is that places of work or study, rest, play and sleep are not separated. Everything is done within the same premises and within one social group, whilst the hierarchy between staff and residents is clearly visible and used to exercise control.

In the literature residential institutions in Eastern Europe are seen as an obstacle to the inclusion of disabled children and places where their rights are too frequently violated (UNICEF, 2005, 2007). Indeed, during this research residential institutions were discussed by almost all participants, not only by people who work in them. The informants from outside of institutions were NGO workers, professionals and government policy makers. Their perspective is considered relevant because of their direct or indirect involvement with issues of residential care. For example some of these informants were previously employed as staff in institutions. It was NGO workers and staff from international organisations especially, who offered the strongest critique of institutions. Using numerous examples, they illustrated how institutions serve as places for exclusion and maltreatment of children and are of more use to the staff who work in them than children themselves. The views from inside

institutions were obtained from staff who work in them and children and young people who live in them.

As discussed in chapter two, institutional care and residential special education is much more widespread in Bulgaria, a country with one of the highest number of institutionalised disabled children in Europe (European Commission, 2009).

Furthermore Bulgaria, together with Romania and Russia has been heavily criticized for poor conditions in residential care institutions (Amnesty International, 2002; MDRI 2006; Bulgarian Helsinki Committee, 2006). In B&H on the other hand there are only 89 disabled children currently living permanently in residential care. The number of special schools is also disproportionately higher in Bulgaria, which has 91 special schools compared to 7 in B&H. Correspondingly, during this research it became evident that residential institutions are a much more problematic issue in Bulgaria, and Bulgarian informants mentioned institutions more frequently. The case of the *Mogilino* residential home shown in the BBC film (Blewett, 2007) is used here to illustrate characteristics of social homes in Bulgaria. The quote below, used as a sub-title, is from one informant from an international organisation (IO) in Bulgaria.

#### 5.1.1.1 'YOU PROBABLY HEARD ABOUT THE NOTORIOUS MOGILINO CASE'

Many would probably never have heard of Mogilino village in Northern Bulgaria, had it not been for the BBC 2007 film '*Bulgaria's Abandoned Children*' directed by Kate Blewett. Those who saw the film saw images of neglected disabled children lying in

their cots, naked, dehydrated and hungry, in the care of negligent staff. The film outraged viewers around Europe, whilst the majority of Bulgarians were shocked that this cruelty was happening in their country. Even though there were those who thought of it as a western conspiracy against Bulgaria, the film played a crucial role in bringing Bulgaria's children's care homes to the attention of international and national policy makers and the wider public. Almost all Bulgarian informants mentioned the film, either as a proof of how bad things are or as an event that initiated public pressure bringing previously hidden issues to public attention. Some talked about the public outrage that inhumanities like this were happening in their country and they gave examples of members of the public organizing demonstrations and demanding that the government take urgent action. Several informants said that Mogilino motivated people to take part in charitable actions and many Bulgarians donated money towards improving the situation in Mogilino.

For some people the Mogilino story was a family drama. The informants highlighted how several citizens disturbed by it rushed to donate money, unaware that their own child also lived there. This transpired months later when these parents got letters asking them to take a child back into the family from the Mogilino home. Some parents did not even know their child was alive let alone that he/she was living in Mogilino. When asked how these people did not know that their own children were in this institution, a Bulgarian informant from an international organisation (IO) explained that some parents thought their children were somewhere else: *'The staff did not bother to keep contact with parents, and there were even situations when parents were told their child had died'*.

The Mogilino film confirmed that institutions served the function of hiding disability in Bulgarian society, a practice in line with '*social automatism*' discussed in chapter two. This was strengthened by pathologising disability and viewing disabled children as 'others' since they are outside the universal construction of childhood (O'Dell, 2003). Within this climate it was acceptable, and even encouraged that parents abandoned their disabled child. They did so, partly because it was not acceptable to have a disabled child, but more often because there was no support for raising such a child. The example of parents who did not know their children were in Mogilino demonstrated the power of denial and socialisation into a collective culture of 'forgetting' disability. When asked whether Mogilino was an isolated case, the respondents in Bulgaria mostly agreed that it was not. In fact many argued that Mogilino was not much worse than any other residential institution in Bulgaria. It emerged that Mogilino illustrated everything that was and still is wrong with institutional care in Bulgaria: *'Suddenly all our officials jumped up and said- no it is not like that- but conditions are exactly like that in most of these places'* (Former government official, Bulgaria).

Indeed, Bulgarian informants from NGOs, INGOs and IOs, as well as parents, agreed that institutions are still places of social isolation that create the opportunity to mistreat and abuse children. They characterised social care homes in Bulgaria as establishments situated in small villages, with no doctors, medical staff or teachers. In addition, social care homes are run and managed by locals, who have no training in care for disabled children. Once human rights organisations entered care homes they found children with physical and emotional development hampered due to lack of appropriate care.

Furthermore the high mortality rates of children in institutions had not raised concerns until recently, with doctors refusing to go to these remote places to investigate. Instead they would just accept and record what the cause of death a member of that institution staff would tell them on the phone. Later investigation into these deaths showed that children died because of inadequate care and poor conditions. Moreover, the Bulgarian informant from an IO commented: *'Staff do not perceive this as a serious problem because they expect these children to die anyway. They think these children died because of their severe disabilities'*. As shown in the example of Mogilino the construction of disability can have extreme consequences or it can in various ways shape the lives of disabled children in care.

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## 5.2 CONSTRUCTING DISABILITY- STAFF IN INSTITUTIONS

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Arguing that discourse plays a powerful role in the formation of identities and the interpretation of meanings, Armstrong (2003) reminds us that in seeking to understand processes of exclusion we need to listen to discourse in different contexts, in order to deconstruct what is being said. When analysing interviews with staff in institutions (see appendix two for full list) in both B&H and Bulgaria, several similar themes emerged. Institutions' staff, unlike other informants, kept stressing that institutions offer protection to disabled children. Furthermore the way they talked about disabled children was very different to that of people from outside. The staff in residential institutions also showed stronger opposition towards social and educational inclusion.



The discourse used by staff in institutions was poignant and examining it gives a richer picture of the characteristics of institutional care.

My immediate impression was that the institutions' staff are oblivious to efforts in both countries to adopt less offensive language in relation to disability. In discussing disability, staff in institutions used derogatory terms such as retardation, or oligophrenia<sup>4</sup>, and one member of staff in a residential institution whispered the word 'idiotia' when describing one disabled boy. This practice is in direct conflict with an understanding that language used to refer to persons with disabilities plays an important role in maintaining negative stereotypes. It also shows little regard for the international instrument, such as the UN Convention on the Rights of Persons with Disabilities (2006) that emphasises the importance of language in combating stereotypes, harmful practices and discrimination.

The discourse in institutions for intellectually disabled children was very different to the discourse in other places visited. Children were talked about, but I was strongly discouraged from talking to them. The main characteristic of staff discourse was: a focus on children's limitations; children were seen as problems, and the staff's work was not deemed valuable. Disabled children and adults were objects of charity and

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<sup>4</sup> The term "oligophrenia" (congenital mental retardation) is described as an impairment of all cognitive functions, without a progressive course, due to pervasive organic injury of the hemispheric structure. Severity levels are: debils (mild retardation), imbecils (moderate), and idiots (profound). There is a further classification into excitable and inhibited types (Davydov, 1983, pp. 231-232) in Gindins (2010).

there was an underlying component that people who work with them do that firstly out of the goodness of their hearts and then for a salary.

The analysis showed that the discourse of staff in institutions is related to their way of working and the organisation of activities, confirming that: *'all discourse is action and all action is discursive'* (Hammersley, 2002, p. 2). For example when talking about residents, the staff in Zavod Breziljek – a residential care institution in B&H, used the Bosnian term *'štićenici'*, which means somebody who is protected or looked after by individuals in a position of power. In this case it is professionals in institutions who have power, usually based on medical diagnoses and their professional knowledge of disability. Disabled children and adults were seen as powerless, objects of protection, without human rights. For example staff in Zavod Breziljek referred to all residents as children, even when they were middle aged or elderly persons. When asked about clarification on actual numbers of children, up to the age of 18, one member of staff responded: *'well that doesn't matter, chronological age doesn't matter for this category of intellectual disability'* (Art therapist, Zavod Breziljek, B&H). It transpired later that only 25 children or persons up to age of 18 lived in this institutions, while the other 354 people were adults. This shows that the staff see intellectually disabled people as in a permanent state of childhood and helplessness, which accordingly justifies their policies of 'protection' or rather overprotection and control.

In addition to protection, the traditional charity discourse was very prominent in all residential places visited in both B&H and Bulgaria. In these establishments children

and adult residents had rooms for making various crafts, ornaments, decorations and pictures. Visitors are usually offered these as memorabilia gifts and these objects are displayed around corridors and in staff rooms for decoration. Children usually make these items as a part of their occupational therapy and staff do not attach any price to these products. As one teacher in a special school in B&H commented: *'it is important that they have a sense of purpose in doing it and they are very happy in these workshops. It is more for them to feel useful'*. What adults and children produce is also used in donors' presentations to demonstrate that residents are benefiting from receiving special educational training and rehabilitation.

In Zavod Breziljek in B&H, residents even had a place for the production of small carpets and, in contrast to special schools, these items were priced. The profit is however not paid to residents, but used for running the institution. Furthermore in this institution disabled adults work on maintaining gardens, gate keeping and cleaning for which they receive a token salary. Since they are not allowed to leave the institution, they use this salary to buy cigarettes and sweets in the institution's small shop. The staff expressed the opinion that disabled people are benefiting from performing this cheap labour, because it makes them feel useful and occupied and gives them a sense of contributing through work. This is, however, not the common reason why residents usually agree to this form of exploitation. Monk (2010) argues that some residents prefer to work as it gives them more freedom and an opportunity to bypass the institutions' rules and restrictions, or as Manning (2008) argues, working residents can have higher status amongst their peers within an institution.

A traditional charity discourse was also encountered in the ways institutions attract donations. In Bulgaria, the principal in a special school reported that they receive unwanted furniture and clothes, usually from successful businesses. In B&H institutions also received numerous donations in food, clothes and money from individuals and organisations. In Zavod Breziljek staff gave examples of how some food companies and supermarkets give them food, instead of throwing it away, once it was close to its use by date. The discourse and actions illustrated here suggest that children and adults in Zavod Breziljek are perceived by staff as being content with much less than non disabled people, such as substandard food, or old clothes that are no longer fashionable in the outside world. As discussed in chapter one the charity discourse and charitable actions are challenged by the proponents of the social model of disability as it undermines disabled people and reinforces a view of disability as tragedy.

#### 5.2.1 WE KNOW THEIR LIMITS

A focus on limitations, when talking about disabled children, was very prominent in both special schools in B&H and Bulgaria. The principal in a special school in Bulgaria gave numerous examples of how children with intellectual disabilities have very limited potential. According to this interviewee, although they have classes in the morning and then again in the afternoon, to repeat what they have learnt, the children cannot attain the results that parents want. Moreover the staff from special schools for intellectually disabled children in both B&H and Bulgaria supported their stories of limitations by highlighting the health problems of children, arguing that these

problems need to be 'corrected' by medical procedures. Furthermore the staff were very doubtful that intellectually disabled people can live independent lives and they used every opportunity to stress this.

The staff in residential places discussed again disabled children's limitations when asked about possibilities for future employment. After primary school, children with intellectual disabilities can only go to vocational school and work as helpers. The principal in a special school in Bulgaria viewed this as a natural outcome of their limitations: *'They will not cook, because they cannot do this, but they will assist and their activities will be supervised by the chef'*. Even when they do find employment, if the young people have an intellectual disability, there is a scornful view of how they perform their duties. For example, the principal in the special school in Bulgaria laughingly, but affectionately, described how one disabled girl does her work. On the whole the staff strongly emphasised that intellectually disabled people can only perform very simple jobs in a protective environment. The staff discourse in residential institutions conveyed a message that intellectually disabled people cannot be contributing members of society.

Discourse on limitations was often put together with altruistic stories of the dedicated care and protection children are given in institutions. In special schools for intellectually disabled children, as well as in Zavod Breziljek, the staff emphasised how much they do for the children and how much children achieve in these institutions. They seemed very sincere when talking about it and appeared to believe very much in

the positive aspects of institutional life. The staff emphasised protection elements throughout the interviews, telling numerous stories about how educationally and behaviourally neglected the children were before they came to their institution or school.

It is notable that special school staff in B&H were more critical of their work, than staff in special schools in Bulgaria and in Zavod Breziljek. However a major difference in the construction of disability was encountered in a school for blind children in B&H. While institutional staff who work with children with intellectual disabilities emphasise limitations and control, the attitude of the principal of the school for blind children was oriented towards children achieving their potential. He very much emphasised individual characteristics of each child and favoured working towards extending possibilities; however this was for blind children only:

*The possibilities for the blind are great. If a child is only blind lots can be achieved with good education. I cannot say that blindness is not a barrier in life, but difficulties can be reduced if a child is given timely attention'.*

Furthermore he did not use a traditional charity discourse and argued that with the appropriate support blind children can overcome barriers and reach their educational and professional potentials. His views were not limited to the idea of one natural childhood. Instead he prioritised children's interaction with the environment and with other people, the perspective that corresponds to the 'new sociology of childhood' (Cooks, 2009).

Based on large-scale research in residential institutions across the United States, Taylor and Bogdan (1998) claims that staff develop shared definitions of residents with intellectual disability and the same phenomenon was observed in residential institutions in B&H and Bulgaria. Taylor and Bogdan (1998) argue that for institutional staff, residents have an object like quality, whilst the division between 'them' and 'us' is a regular frame of reference. Coupled with the perceived need for strict control of disabled people, this indicates that staff do not see disabled people as equal human beings. For example the staff did not hide their surprise that some residents wanted to have nice clothes, cosmetics, hair products and a mobile phone. Even a young member of staff in B&H, an art therapist, who did not have disability training in the old system, accepted a 'them and us' discourse provided by older staff and expressed surprise that 'protectees' are interested in fashion with some of them wearing the same clothes as herself.

Furthermore, the staff in B&H did not hide their disapproval when it came to people with intellectual disability having children, emphasizing the need for gynaecological control and monitoring of residents' sex lives. It transpired that several couples who live in Zavod Breziljek in B&H are monitored. A member of staff explained their institutions' policy: *'We observe their behaviour and if they argue we try to reconcile them...we have some couples who are living together as a family, but they sleep in separate rooms'* (Group interview, Zavod Breziljek). Furthermore, staff do not refrain from advising how these people should manage their relationships, so that adolescents in institutions

are taught that adult relationships for disabled people are about friendship and not sex. Whilst an increase in more positive attitudes and acceptance towards sexuality of people with intellectual disability is reported elsewhere (Gilmore & Chambers, 2010) staff in Zavod Breziljek control opportunities for intimate relationships. These restrictions and lack of clear communication about disabled people's needs can have dramatic consequences, as illustrated by this story from Bulgaria:

*One woman with an intellectual disability fell ill and she was taken to hospital, where she was, without her consent, subjected to an operation and doctors' removed her reproductive organs. Then one day after she was released from the hospital she ran away from her group home and nobody could find her; the worst of all is that they could not understand why she had run away...nobody connected these two events' (INGO worker, Bulgaria).*

Research by O'Driscoll and Walmley (2010) argues that absconding is more common than acknowledged and is the way in which residents with intellectual disabilities are showing active resistance to incarceration and the way they are treated.

It was also noted that staff in residential institutions want to differentiate themselves from residents by emphasizing their position of power. In Zavod Breziljek in B&H, staff strongly objected when their former manager tried to introduce new practices, including advising staff to stop wearing white medical coats. In this resistance it is possible to recognize the underlying need to hold on to power, so staff interpreted taking off white coats as stripping them of their symbolic power, thus reducing the gap between them and residents. In addition the stories of institutional harassment, misuse of resources and corruption in this same institution were encountered in the report by a human rights organisation (Ombudsman B&H, 2009). These were also reported by other informants, but not those working in the institution. The staff in this institution



and other residential places communicated that they were united and supportive of each other in their efforts to provide the best care for disabled children.

When discussing obstacles for change in institutional care, outside informants often mentioned older professionals educated in the previous system. However, the interviews in institutions revealed that younger and more recently employed members of staff in both B&H and Bulgaria accept traditional institutional discourse, their views converging with established members of staff who have been working there for a long time. They used discourse employed by older staff members, nodding and agreeing with what they said in their presence but also when they were interviewed alone. Taylor and Bogdan (1998) argue that institutional staff develop shared definitions with those around them because they spend a great deal of time with one another, talk about past events, share stories and experiences and explore meanings in a concentrated way. This might present a problem, as inclusion requires challenging assumptions, reflecting on professional practices and re-examining constructions of disability (Booth et al., 2000).

In addition, the social construction of disabled children, as well as the need for personal and intimate care, increase their vulnerability to various forms of abuse (Westcott & Cross, 1996; Cross, 1998). Disabled children in residential care are commonly subjected to psychological, physical and sexual abuse (Carter, 2005). Neglect appears to be the most common form of abuse of disabled children arising from ignorance of their needs, especially the need for stimulation (Cross, 1998).

According to Peake (1997), because they are away from home, children are additionally vulnerable and less able to speak out. The topic of this thesis was not to investigate the abuse of disabled children, as that would require a different methodological approach. Nonetheless, in the context of residential care, the importance of this topic needs to be acknowledged, especially since abuse of disabled children in residential institutions across Eastern Europe has been reported consistently (Bulgarian Helsinki Committee, 2002; MDRI, 2006). These reports dealt with neglect, extremely poor living conditions, undernourishment and chaining children to their beds, but not with the sexual abuse of disabled children.

The whole context of residential care creates opportunities for abuse (Roberts & Hamilton, 2010; French, 2010), as confirmed in this study. In Bulgaria, children's homes are in remote places where neglect and mistreatment of children has been going on for years and this has been reported in the literature and by informants from IOs and NGOs. No reports of this kind have emerged from B&H, where institutions are not so secluded and they frequently have visitors from outside. Still this does not guarantee an abuse free environment. It transpired that abuse is something the social workers in this study did not like discussing. When I asked them about protocols in reporting abuse they were taken aback and appeared suspicious about my motives. There does not seem to be recognition that disabled children are more vulnerable to abuse due to the power imbalance and because they are easily silenced, as argued by Cross (1998). In addition as reported in both countries, the social workers who inspect homes most often do not talk to children. They talk to staff and inspect documentation.

This approach does not allow children to report abuse and it is something that needs to be addressed in safeguarding children's wellbeing and addressing malpractices.

### 5.3 OUTSIDE INCLUSION: THE LIVES OF CHILDREN IN RESIDENTIAL INSTITUTIONS

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In portraying the life of children in institutions I will depend heavily on children's voices, personal observations and analysis of institutional songs. In this section the most space is given to lives of children in Zavod Breziljek in B&H. This is because this institution was studied in depth and the most complete stories about children and their lives were accessed there. However, these stories are not exclusive to children in Zavod Breziljek, instead they highlight important issues of rights, participation and abuse common to many disabled children in care. Even though it was not possible to interview children living in residential care in Bulgaria, observations of the conditions they live in and proxy stories of staff and other informants provided some insight into their lives.

#### 5.3.1. LIFE BEHIND A FENCE

In Bulgaria children are placed in institutional care for social reasons, mostly because of poverty and because parents are not supported to care for their children at home. This is somewhat true for B&H, but in B&H it is much less likely that a disabled child will be institutionalised and if that happens social workers report that it is only after all

other possibilities have been exhausted. It emerged that there are various reasons why children ended up in Zavod Breziljek in B&H. For example one boy was abused by his father, because he had a disability. Another two children were there because their family was very dysfunctional and could not cope with their disabilities, so social services placed the children in state care. Once a child is placed in an institution, the family ties often break:

*...and then when they placed the child in an institution, most of them considered that the problem was solved. Some of them come here occasionally, some never...simply that obligation of family towards the child is taken away, once the child is placed here.  
(Defectologist, Zavod Breziljek)*

The staff in the Zavod Breziljek reported that many children who come to the institution are likely to stay there for the rest of their lives. According to one member of staff only 6-7 children were reintegrated back into their families in the last 31 years, out of 1200 residents who lived in Breziljek throughout that time. Furthermore, for these children contacts with family were infrequent, as some families live in towns far from this institution, which involves high transport costs. Although it does not happen often, children said they love it when parents came to see them and they love to go home: *'The other day he (one of the interviewed boys) was complaining and he asked me why his parents are not coming. I said to him they probably cannot come because it's cold'* (Teacher, Zavod Breziljek). The staff interviewed in the special schools in Sarajevo said that some children miss their parents and suffer emotionally. They were aware that this arrangement of separating children from their parents is not a good solution, but they justified it by the lack of opportunities for their education in the children's home towns.

The children interviewed in Zavod Breziljek have different levels of learning difficulties and significant communication impairments. Still, once we established communication, the children were able to express their preferences, and with the help of their teacher, convey some things about their lives. Several themes were common to all of them. They all experienced traumatic life events: such as physical abuse, death of a sibling or life with alcoholic parents. The staff revealed that some children are emotionally needy and have difficulties in adjusting to life in the institution, which does not come as a surprise, considering the grave experiences some endured. For example one 17-year-old young man talked about his life on the streets, which involved abuse by strangers, extensive alcohol consumption, cigarette smoking and drug abuse. When visitors come to the institution he goes cap in hand asking for cigarettes and money. When asked about the future he said: *'I would like to go to Germany...I would find a nice wife and a job; I would work there. I've had enough of Bosnia. I just need a chance to get out of here...they have a better life there'*. His needs and vision of the future do not accord with the views staff hold about disabled young people and their limitations.

The children from Zavod Breziljek in B&H said they liked socialising with their peers and the activities they are engaged in. However, they all said that being able to explore life outside the institution is something they desire, but do not often have the opportunity to do. When asked why that is so, one boy said: *'management decision'*. Exploring the outside world usually consists of hanging out in the institution yard with other residents, an exploration that ends at the tall fence. The residents show enormous excitement when a car pulls up in front of the main building. Usually they

all gather around to greet visitors, talk to them or ask for something. However, this is usually done by the older residents, as smaller children are taken outside only by the staff. The staff were aware of the children's need for more outings and they talked about occasional trips to the cinema, holidays on the Adriatic coast or a visit to a fair. However, the staff explained that they cannot organise more outings because they only have a small van which can take a limited number of children at one time, so going outside the institution is not often on the agenda.

The grounds around Zavod Breziljek are nicely kept with trees, flowers and benches. There is also a small makeshift swimming pool. In summer time residents splash in the pool, play football or netball or just lounge around in the shade. For a moment one can think that this is an ordinary summer camp, but the tall fence around signifies that the outside world is not within easy reach. Furthermore, the presence of staff in white coats gives the whole atmosphere a medical, instead of a holiday feel. Residential special schools are much less medicalised, even though staff in medical coats were occasionally encountered. The special schools overall are more children's places, whilst in Zavod Breziljek, children were very much outnumbered by adult residents.

With two older boys in Zavod Breziljek I explored their feelings towards girls and relationships a little bit. One boy said that he wants to get married and have a family. The other boy said that there is nobody that interests him in that sense. The staff in institutions said that older boys have interests but they have very little opportunity to meet someone their age, because it is mostly adults who live in their institution and

trips outside are rare. It emerged that the boys did get interested in girls from a mainstream hairdressing school, who used to do their practical in the institution, but the girls never came back once they had finished their placements.

### 5.3.2 CHILDREN'S VOICES IN INSTITUTIONS

As discussed in chapter three professionals in institutions attempted to exclude children from this research. Their considered view - that the voices of disabled children are irrelevant - is connected to their perception of these children and their abilities. A defectologist in Zavod Breziljek did not hide her surprise when I asked to interview children. Referring to her professional knowledge she firstly tried to discourage me from talking to children, but then resorted to giving me instructions: *'When you talk with those children, you need to limit yourself to some 100 words so that they can understand you; and not only for that reason but also to get answers to the most simple questions'*. The other staff in the same institution supported that view, apart from one teacher who thought that interviewing children would not be a fruitless job. She supported the interview with each child by giving me their family histories, talking about their life in the institution and helping in interpreting their responses.

The strongest opposition, however, to talking to disabled children came from the principal of a residential special school in Bulgaria. She did not even want to consider it, justifying it with children's limitations, but more with the concern that we (the interpreter and I) might frighten the children. After an interview with her she

suggested taking us around the school and classrooms. We were again firmly reminded not to ask children any questions. She opened the door to a small stuffy classroom where children sat still in their benches. There were 12-15 children who looked at us with curiosity. The teacher's desk was at the front. The principal clearly signalled that we were not welcome to enter the classroom by positioning herself at the door, thus acting as a barrier between us and the children. This only gave us a chance to peek inside. The principal used the opportunity to tell us how severely disabled the children were and how the teacher struggled with them. The same happened when she took us to a second classroom.

It was evident that in this school disabled children were talked about but not given a chance to be talked to. The school principal was an example of how powerful actions by professionals are and how much control they can exert over the lives of disabled children. Furthermore it transpired that in both B&H and Bulgaria, special schools apply the same practices even when the state monitoring and evaluation agencies are visiting. The people from these agencies do not talk to children, as mentioned earlier. There is no practice where disabled children are asked for their opinions or how they feel about something. For example one boy in Zavod Breziljek mentioned missing his family and not wanting to be in the institution. When asked whose decision it was he simply replied: '*socials*' (short for social workers). This lack of participation is in strong contrast to inclusion philosophy and is a direct violation of children's rights, as discussed in chapter one. The staff in institutions however did talk about rights, but their view of them was restricted to protection, the need to improve health care and the institutions' facilities, whilst the participation component was never mentioned. This



view corresponded to their constructions of disabled childhood and the idea that children are passive recipients of adult care, instead of active agents and holders of rights.

### 5.3.3 INSTITUTIONAL CEREMONIES AND SONGS

The term 'institutional ceremony' was used by Goffman (1961) and refers to all social events in residential institutions. During the research in B&H I took part in one whole day's institutional ceremony in Zavod Breziljek. It was a day when international donors were visiting and a special program was organised by staff. The institution's manager and donors gave speeches about the importance of improving the lives of children in institutions; the importance of creating better conditions for disabled people and achieving inclusion in society. The residents were not offered the chance to say anything; instead they performed their rehearsed songs and dances on the stage. The audience was visibly moved and emotional. The residents proceeded to give us gifts they prepared, and they consisted of souvenirs they had made. Presumably this was to suggest their gratitude for our visit and attention.

The ceremony proceeded to another place, a nearby village where some small homes, built to re-house some residents, were showcased. Again more speeches were delivered by donors, and this time they were recorded by a television crew. The view was that this type of living represents a move towards social inclusion. Still, there was no voice from residents, who waited inside the perfectly tidy house, to greet the

visitors. After the speeches everybody walked through the house. The guests were then taken for lunch to the seminar room in the main building. This lasted for several hours during which nice food and drinks were served and guests were mingling and engaging in conversations. Again no residents were present.

According to Goffman (1961) occasions when outsiders visit residential institutions can be also classified as institutional ceremonies. Visits to special schools in Bulgaria resemble Goffman's classification closely. The interpreter and I were taken around by the school principal and showed classrooms and displays of crafts and pictures made by children. The talks with children were often made impossible and the staff that got involved in our visit seemed to talk only along institutional lines. We were not left alone at any moment but the impression was that every effort was made to send us away convinced that life in institutions is best for intellectually disabled children. Goffman (1961) argues that institutional ceremonies, such as Christmas parties and theatrical plays in total institutions, can temporarily reduce differences between staff and residents, and provide role release and reversal of usual social roles. This was, however, not the case with the institutional ceremonies observed in this study. It might be that the character of the ceremony or presence of large numbers of outsiders prevented this from occurring, or the divide between intellectually disabled residents and staff was too great.

During the institutional ceremony in Zavod Breziljek residents sung several songs, one of which was introduced as their institutional hymn. Also during the time I spent in

this institution I frequently heard residents humming or singing these songs. These songs and music are the original work of residents, and reproducing them in a proper music CD was supported by a foreign organisation and professional musicians (Salcin-Watts & Salcin-Watts, 2007). This is not a surprise as disabled people frequently use songs and poems to comment on social oppression and prejudice (Cameron, 2009). As already described, visitors are not encouraged to talk to children with learning difficulties, and they do not get much opportunity to discuss their feelings, fears and hopes. In that respect, interpretation of these songs is valuable as residents use them to communicate something about themselves, but it is also as insight into the institution's and societal discourse. A full text of translated songs is available in appendix six.

The music and lyrics of the first song, regarded as an institutional hymn, has a very emotive tone. It is a song in which the institution is regarded as the only home; however the final verse tells about longing for the natal home: *in my mind I often fly over the wire; my thoughts carry me, I want to fly, to land for a moment' in my family home* . The second song is a call for friendship and tells us that disabled children want friendships, but this is not easy to achieve. A verse that says '*your star might be brighter than mine*' indicates disadvantage. The third song is sung by a child and it tells about routines in this institution, as well as an emotional connection between residents themselves and with staff. However the overarching theme in this song is the secret nostalgia children feel for their mothers: ...'*When the night comes and darkness falls and children's sleep comes over us, quiet and daring like from a tale, the face of a mother appears before our eyes*'.

These three songs are sad, but moderate in tone. In all three songs children go home in their dreams or imagination, implying that the desire is unrealistic, whilst life in institutions is their only certain reality. The fourth song, however, is very different to the other three. The song is written in a style of a '*sevdalinka*' song, which is a unique type of folk music developed in Bosnia in the 15<sup>th</sup> and 16<sup>th</sup> centuries. The '*sevdalinka*' type of song is dominated by melancholic, evocative tones and slow rhythms. The songs are usually emotionally charged and contain longing for something lost or gone, most frequently love or home. This one is not moderate, like the previous three songs, but is a very sad and weepy song. Being an orphan is described in this song as an ultimate tragedy. In any case '*siroce*' (an orphan) in the Bosnian language carries the saddest connotations. This song was not originally supposed to appear on the CD, but residents insisted on including it. The underlying story of this song is being alone and abandoned, and this is something that had been reported by interviewed children too.

Even though conditions in institutions might not always be bad, as was the case in B&H, the impression I got from talking to children, staff or people from outside is that placing children in an institution, especially permanently, is a tragedy in itself. It strongly implies abandonment, disadvantage, removal from family and losing touch with family. Grunewald (2003, p. 3) argues: '*The trauma of being involuntarily separated from one's parents, friends, and familiar home environment creates a fundamental conviction of being unwanted and powerless, of being an object, rather than a unique individual*'. In addition there is a broad agreement in international child care policy that institutional care negatively affects the social and physical development of children. It is also agreed that the practice of institutional care perpetuates social exclusion. This is accepted by

governments of the Eastern European countries and various deinstitutionalisation programs and strategies are currently being implemented, as discussed in the next section.

#### 5.4. DEINSTITUTIONALIZATION – POLICIES, PRACTICES AND RESISTANCE

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As discussed in chapter two, in B&H deinstitutionalisation is not an urgent policy priority because the proportion of children living in institutions is not as high as in Bulgaria (Stubbs, 2007). Bulgarian participants agreed that institutions are in a terrible state, and frequently talked about processes for deinstitutionalisation, reflecting on present policies and strategies. The policy choices of the Bulgarian Government seen as a way to replace institutional care are: prevention of abandonment of children, day care centres for children and adults with disabilities, centres for social rehabilitation and integration, supported homes for people with mild intellectual impairments (Government of Bulgaria, 2006, United Nations, 2009). Some projects are funded by the EU budget and some by the Bulgarian government. In 2004 the Ministry of Labour and Social Policy started to implement a large scale EU supported PHARE<sup>5</sup> 2003 project, 'Improvement of the quality of life of people with mental disabilities', with the idea of promoting and developing alternatives to institutional care. The project also

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<sup>5</sup> 'The PHARE programme is one of the three pre-accession instruments financed by the European Union to assist the applicant countries of Central and Eastern Europe in their preparations for joining the European Union'. Source: [http://ec.europa.eu/enlargement/financial\\_assistance/phare/index\\_en.htm](http://ec.europa.eu/enlargement/financial_assistance/phare/index_en.htm)

incorporated training for social workers in Social Assistance Directorates<sup>6</sup> and for staff working at the specialised institutions.

Indeed, during interviews with Bulgarian government policy makers, their efforts and willingness to reduce the number of children in institutions was repeatedly emphasised. They praised development of their community resources such as day centres and rehabilitation centres as a good alternative to institution. Whilst government policy makers mostly communicated successes, other informants argued that the state agency working on this issue does not have strategic plans and does not know how to address this problem in an efficient and productive way. Several participants mentioned a lack of alternative services:

*Yes, deinstitutionalisation is high on the government's agenda, but it happens to be very difficult especially because to close the institution you have to have all other support, especially family support services developed, because where are you going to put children; and these are not developed (NGO worker, Bulgaria).*

Furthermore, in discussing deinstitutionalisation strategies, informants in Bulgaria agreed that more attention is given to what will happen to people who work in the institutions and buildings if children are offered alternatives: *'They never think, they never put children first and their best interest... it's the building, the staff and eventually children'* (Policy maker, IO, Bulgaria). Also informants from NGO, INGOs and IOs agreed that the strategies such as family reunification are underdeveloped. In spite of

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<sup>6</sup> Social Assistance Directorates are government structures promoting social protection related to the Social Assistance Agency, the Child Protection Department and the Ministry of Labour and Social Policy. Source: Mestan (2006)

numerous criticisms of government policy, most of the participants did agree that deinstitutionalisation is on the agenda of the Bulgarian government, but one that is difficult to achieve.

In B&H the policy efforts are on preventing further institutionalisation and improving conditions and transforming the few existing institutions. The approach to the reform of large institutions in B&H was encountered in projects implemented by the Zavod Breziljek, the efforts supported financially and technically by one international and one national NGO for children and adults with intellectual disabilities. The project started in 2007 and smaller housing units had been built in a nearby village, for relocating their residents, as discussed previously. Depending on the size of each house, they accommodate 5-12 residents, usually children and young people with intellectual disabilities. They live in the house with professional support, but the idea behind the project is to foster independence and to develop community living for people with intellectual disability.

The project is understood and promoted in B&H media as a pilot project of deinstitutionalisation and as a new approach in accommodating disabled children and adults, an approach which is closer to European Standards. However, it is difficult to say if this is a deinstitutionalisation project or the reform of an existing institution. The relocated residents still have their education and rehabilitation in the old institution and have little contact with the village community. This appears to be relocation and improvement in housing conditions, leaving all other aspects of the institution in place.

The staff in Zavod Breziljek expressed the desire to be part of the new trend, but their interpretation of it was not exactly in line with inclusion philosophy. They were very proud of building new houses within the institution declaring it as a move towards integration. If they were critical of anything they do, they usually blamed financial resources and not their approach.

#### 5.4.1 STAYING WITH AND GOING BACK TO FAMILY

The UN Convention on the Rights of Persons with Disabilities (2006) stresses that States must ensure that children with disabilities have equal rights with respect to family life. Furthermore, States have to prevent concealment, abandonment, neglect and segregation of children with disabilities. The Convention states that in no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents (article 23). This provision means that large residential institutions will have to be phased out, whilst practices that separate children from families need to be changed. Family reunification is recognised as a deinstitutionalisation strategy (Davis, 2005) and this has been attempted to an extent in several institutions in Bulgaria. However informants from Bulgaria argued that social workers and staff in institutions still neglect the family as a resource, even when implementing deinstitutionalisation projects.

As explained by a Bulgarian informant, the opinion among people working with disabled children is that these families would not want their children back, so they never put any effort into building relationships with these families. Even those who



started projects on building alternatives for children from institutions did not realise this straight away and the family was overlooked for some time. However this informant argued that this opinion is unjustified:

*If you explain to them what kind of services they can get, what additional financial support a family can receive, they are willing to accept their children back. So it is an area that has not been explored and that is still not at all worked on (International organisation, Bulgaria).*

The informants in Zavod Breziljek in B&H said they are trying to re-establish cooperation with families. They gave the example of Croatia where they have seen parents taking part in the activities, and stated that they would like to do something like that. The problem is that residential institutions are most often not close to the parents' home and visiting has to involve costly and time consuming travel, not easy for some parents to afford.

An additional problem is that in both B&H and Bulgaria residential care institutions receive more money than parents or community services, which directly contradicts the inclusion philosophy and rights agenda. In Bulgaria in 2008, per client standards were introduced for financing residential placements. So a child deprived of parental care, who is often in an institution for disabled children, receives 1,800 euro per year for a school age child and 2,700 for a preschool age child. Non-residential day centres receive 2,500 euro. In B&H a residential care institution accommodating and providing care for a disabled child receives an even higher amount per resident (around 3.900 euro per year) from social services (Ombudsman of B&H, 2009). Parents of disabled children never receive this amount of financial support, even though there is recognition that poverty is a significant reason why parents resort to institutional care

as well as a cause and consequence of social exclusion. Still redirecting resources from institutional care to family does not seem to be a straightforward process. Social workers in B&H, parents and staff from local and national disability NGOs thought of it as a good way to support families and prevent institutionalisation. On the other hand Bulgarian government officials and several policy makers from international organisations were against this option. They reasoned that supporting families financially would increase their dependency or that the money will not be directed to the needs of children, but used for other family purposes.

Neglect of the family as the main resource in preventing new children from entering institutions in the first place emerged strongly in this study. A parent from a parents organisation in Bulgaria, talked about the need to establish regular parents' centres: *'Since our organisation has been talking about deinstitutionalisation this is the first thing to do, to think about this early intervention process as a first step in providing services for children with disability'*. From children themselves, as well as from other informants it is fairly easy to conclude that children do not have a choice about being sent to an institution. Once institutionalised, these children lose contact with their family and community and they reported developing relationships in the institutions where they currently lived. With programs for deinstitutionalisation taking off, children are sometimes being moved to different living arrangements. Unfortunately, in this process some of the same patterns are happening as with process of institutionalisation. Somebody else is deciding who will be deinstitutionalised, how and when.

#### 5.4.2 RESISTANCE TO DEINSTITUTIONALISATION AND EDUCATIONAL INCLUSION

Resistance toward deinstitutionalisation projects and social inclusion was more prominent among people working in residential care and special schools rather than parents, policy makers and NGO workers. One policy maker from Bulgaria described an instance in which teachers from special schools had organised demonstrations against the perceived closure of their school, bringing with them children from the school. The resistance was also more prominent in regards to children with intellectual disability and complex health needs. For example staff in Zavod Breziljek, acknowledged that it is unjust that the family receives much less money for care of disabled children than residential institution, but then they proceeded to justify this policy choice:

*In a family that child cannot get professional support ...then parents would have to take the child every day to special school. ...than you can have abuse...now we have foster families, but there is a big question if children in those foster families can have a dignified life; they take disabled children but you don't know what is their motivation for that... most often it is money (Zavod Breziljek, B&H, group interview).*

Participants in the residential special schools in both countries had a lot to say about educational inclusion, but analysis reveals much stronger resistance to change and inclusion in Bulgarian special schools. The principal of a special school in Bulgaria expressed resistance to inclusion on a number of occasions during interview and this is just one example: *'children here feel better... even though they have these mental disabilities- oligophrenia, they have feelings... this integration would be very good for children with physical disabilities, but with mental and intellectual disabilities this would be very difficult...'*. Other members of staff in the special school in Bulgaria openly criticized inclusion

initiatives saying that very soon the authorities and parents will realise it is unrealistic and then they will want to re-establish special schools. They said they do not feel threatened by social and educational inclusion initiatives, but they kept justifying their work and the existence of their school during the interview. The principal in a special school in Bulgaria gave the example of children with health problems and incontinence in support of her argument that inclusion cannot work for them. In both countries these views were usually attached to expressions of concern for children:

*If you like, I can show you one of these children; they cannot be placed in such an environment (mainstream school). It is not good for them and of course not good for other children in that environment. Primarily we have to plan something that is in the best interest of the child, and being in such an environment is not in the best interest of the child. With this we automatically imperil other children in the mainstream (Defectologist, special school, B&H).*

Yet the account about educational inclusion given by the principal of the school for blind children in B&H was very different to those obtained in special schools and care homes for intellectually disabled children. This principal insisted on an educational component, even though they organised other activities for children who live in the school as well. Furthermore, this informant highlighted that their education establishment is there so that parents and children can have a choice, and nobody should be strictly advised what school to attend.

Even though resistance to inclusion was evident among special schools in both countries, in B&H, unlike in Bulgaria special schools are making efforts to take part in projects on educational inclusion. They believe they can offer expertise in this area and

special schools in B&H work on supporting inclusion through mobile teams that go to communities and support parents:

*Apart from our usual activities in education and upbringing, we have one group of people, who besides their regular duties in the school, work in the community. We called it a mobile team. For example if we find out there is a blind or visually impaired child in some other town (we are given this information by the association for the blind) we offer ourselves as some kind of service to the family and then we work with parents and with the child. It is most important that parents have decided to work with a child; the earlier they start, the better it is. If a child is here in the school, then we maintain regular contact and cooperate with the parents...in the future we plan to open some type of resource centre for parents...(Principal, special school for blind children, B&H).*

However, even though they offer their expertise, staff in a residential school for children with intellectual disability in B&H complained they are frequently excluded by government and international organisations, when inclusion projects are implemented. This was the case in Bulgaria too, where the majority of informants noted that policy makers do not communicate well with staff from special schools. It is further reported, that this lack of communication, especially in Bulgaria, increases resistance to inclusion among special schools' staff. Several informants in Bulgaria stressed that special schools feel threatened by integration because they see it as a direct risk to their jobs and livelihood. A government policy maker from Bulgaria gave an example of demonstrations organised by one special school when rumours about closure reached them. Also in Bulgaria special schools safeguard from closure by attracting Roma, whose parents prefer special schools for social reasons. However, the principal of the special school in Bulgaria strongly claimed that all children in her school are moderately or severely disabled, arguing that she does not know how many children are Roma. Including Roma children in mainstream school would significantly reduce the number of children in special school in Bulgaria, thus making these schools

even more vulnerable to closure. In B&H staff in special schools did not express concern about the threat of closure.

The resistance to inclusion is not only evident among special schools in Bulgaria. Great resistance to social inclusion comes from the general public. For example when the Bulgarian government announced plans to build group homes to re-house children from the residential institution, Mogilino locals organised demonstrations against it, arguing they did not want houses for disabled children in their neighbourhood. This example shows that the social climate towards disability is slow to change, which undermines inclusion initiatives.

This chapter showed that children placed in institutional care are currently de facto outside the inclusion agenda. The participation of children in care and opportunities for self determination are almost completely absent. Looking from the social model perspective, children and young people are prevented from exercising their rights in residential care due to economic and social constraints, but this is often the case for non disabled children too, as children are overall the economically most disadvantaged group (O'Dell, 2003). Moreover taking into consideration a social constructionist perspective, the social exclusion and violation of rights is happening because disabled children are viewed as helpless, needy and persons who will never be able to contribute to society and achieve personal autonomy. The dominant view is that they need constant protection and control as in the mainstream world they will not be able

to cope because their impairment. This view is used as a major justification for maintaining segregated facilities.

For Finkelstein (1993) incarcerating disabled people in institutions is the ultimate form of social exclusion and oppression and the way for disabled people to lose control over their lives and become socially dead. Even though I support this view to a great extent there are several factors that, in the current climate in B&H and Bulgaria, introduce complexity to the issue. For example, currently, since inclusive options are largely unavailable the only way for disabled children to access education, prepare for later life and participate in social activities is to attend special schools. During this research examples were given of children who were permanently kept at home and treated as ineducable before they accessed special schools. In those cases special schools meant some form of social inclusion. Additionally this chapter has shown that in some cases (for example, the school for blind children) residential care is a temporary phase that will prepare children for inclusion in mainstream society, but also develop a positive identity related to blindness, as previously reported by French (2004). This shows that the special/mainstream dichotomy does not necessarily mean a straightforward exclusion/ inclusion division. Memories from institutions can also sometimes be positive, often in relation to friendship or participation in sporting activities (Hreinsdóttir & Stefánsdóttir, 2010) and this has been reported by children in Zavod Breziljek.

The chapter also shows that residential care homes and special schools are very entrenched in both countries, especially in Bulgaria and after the 20 years of transition these establishments are still going strong, with many of them untouched by inclusion initiatives. Furthermore deinstitutionalisation programs are happening too slowly or in an ad hoc fashion. The overall tendency is to close the institutions down completely like they are trying to do in Bulgaria, but the process is proving to be too slow. In B&H on the other hand institutions are attempting their own reform, which sometimes reproduces institutional culture, as seen in the example of Zavod Breziljek. The problems with deinstitutionalisation are plentiful and Mansell (2006) highlights several problematic issues. In a market based system the focus is on cost rather than quality, resulting in under-investment, whilst the domination of a particular ideology creates a situation where services are judged by their intention instead of result.

Mansell (2006, p. 73) also argues that with the rise of the social model of disability, attention has shifted towards de-differentiation of disabilities and staff training in anti-discriminatory practices, rather than in the professional support which will increase the skills of people with significant intellectual disabilities. In Bulgaria, where institutions are in poor state (Bulgarian Helsinki Committee, 2002; Blewett, 2007), alternatives such as independent living and group homes are not questioned for quality. In B&H however, these issues emerged from the interviews when several professionals questioned the safety, quality and performance of small group homes for young people with intellectual impairments organised by NGOs and people who are not disability specialists.



Moreover my understanding is that alternative strategies of how special schools and institutions can be transformed and brought closer to the inclusion agenda are underexplored. UNICEF (2005, 2010) gives examples from the Region, of special schools and residential care transforming into resource centres providing professional services to inclusive places and support for parents and children in transition for children living in residential care. Another potential for residential institutions is respite care centres, an opportunity completely absent in B&H and Bulgaria. However in attempting transformation of institutions there needs to be a realistic assessment of the professional and physical capacities. As already presented in this chapter in Bulgaria many residential places are in remote locations, usually staffed with locals who are not professionals in child care or education. The informants from IOs, INGOs and NGOs argued that places like this have little potential for change and transformation and that the only option is closing them down completely. Apart from deinstitutionalisation strategies, this research also identified promising examples of preventing institutionalisation in the first place by increasing the development of community services as discussed in the next chapter.

## CHAPTER 6

### PROFESSIONAL PRACTICES AND COMMUNITY CARE

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Services such as education, social care, health care and community centres are all part of a context in which the disabled child lives and interacts. Acknowledging the relevance of the context for making inclusion possible, this chapter examines to what extent these services in B&H and Bulgaria facilitate or obstruct the development of social inclusion. History and literature on traditional government services such as education, defectology, social care and categorisation commissions were introduced in chapter two. Building on that background, this chapter firstly presents how these traditional state services respond to the inclusion challenge. The second part looks into new community services currently being developed and promoted in B&H and Bulgaria, such as day care centres, opportunities for independent living, and foster care programs. Finally I will identify what services are missing and examine whether philosophical and conceptual changes are taking place. The chapter begins by considering the education sector.

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#### 6.1 EDUCATION FOR DISABLED CHILDREN

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Before 2003 Bulgarian children with *mild* intellectual disabilities were excluded from mainstream schools and placed in special schools, while children with more severe intellectual disabilities were regarded as “ineducable” and placed in institutions or

cared for by their parents at home with no educational options (Open Society Institute, 2007, p.3). The situation was similar in B&H and children with special needs were educated in special classes within mainstream school or special schools. The shift in national policies happened in B&H and Bulgaria at around the same time (2000-2003) with the adoption of education policies that emphasise non-discrimination and the right to education, and emphasise the inclusion of disabled children into mainstream schools (Tsokova & Becirevic, 2009). As presented in chapter two, there is a general commitment among national policy makers, as well as pressures from the international community, to develop an inclusive orientation in education.

This research identified changes in the education of disabled children in both countries.

A defectologist from a special school in B&H reflected how this change is observed in practice:

*Before this law, children with moderate and severe retardation did not have access to school...it was discrimination. Now the law on primary and secondary education since 2003 gives the possibility to every child to go to the nearest mainstream school and children with mild mental retardation usually go, whilst here we get children with moderate and severe retardation or children with mild retardation and health problems.*

The same trend was not reported in special schools in Bulgaria, however Bulgarian policy makers claimed that more children are being integrated into mainstream schools.

In respect to special education in B&H and Bulgaria, some strong differences emerged.

The network of special schools was much more developed in Bulgaria, than in B&H.

There are 91 special schools for the education for children with intellectual disabilities alone in Bulgaria, compared to 7 special schools in total in B&H. In B&H special schools are based in city centres and town centres, whilst in Bulgaria they were on city edges or in villages. Also there was more resistance to inclusion from special schools in Bulgaria (see chapter five). Staff in the special schools in B&H had doubts about inclusion, but wanted to be part of inclusion initiatives.

Even though informants in special schools in B&H spoke positively and optimistically about inclusion they were against inclusion in certain conditions and one defectologist formulated it as follows: *'some parents insist that children go to mainstream schools...but it is sometimes more the wishes of parents and the satisfaction of their ambitions than the best interest of the child...and then the child is isolated in those schools'*. Furthermore, participants from special schools in B&H talked about special school as a transition period for a child, a place where a child will be prepared for inclusion in society:

*I think for these children it is more important that special schools find ways to include them in society; it means that we go to various community events, walks through the towns...and that parents do the same...for them it is not inclusion if they go to mainstream school and then sit there isolated...(Defectologist, special school, B&H)*

The big issue in Bulgarian special education is the over-representation of Roma children, with 51% of children in special schools in Bulgaria being Roma. These children are placed in a special school not because they have special educational needs, but because parents and professionals see special school as places that can address their social disadvantage, by providing them with a place to live and food (Open

Society Institute, 2007). This issue contributes towards the misinterpretation of national statistics on disability and causes confusion when establishing how many children have been transferred from special schools into mainstream schools, because it is not possible to tell if these children are disabled or Roma. In addition, attracting Roma children into special schools contributes towards bringing numbers up in special schools which safeguards from closure. The education of Roma children in special schools strongly perpetuates social exclusion, and discrimination against the Roma. It also presents problems for disabled children attending special school:

*We sent him to an ordinary kindergarten in a speech disorder group...he improved and had no problems, neither with teachers nor with other children. He learned the letters and how to count up to 10 and backwards and he was included in all celebrations.... Then again after the recommendation of specialists, we enrolled him in a special school. He stopped speaking; he was the only Bulgarian child there, all the others were from the Roma population, and spoke the Roma language and he could not communicate at all (Rosa, mother Bulgaria).*

Negative practices from one a semi-residential special school have been also reported in B&H, such as the resistance of staff to adapt to new ways of working. Also, there were examples where the interest of an institution was put before the interest of the children. A former institution employee, currently working in a centre for social work, expressed the following concerns:

*Some institutions adjust classes at the children's expense just to secure government support. An institution receives almost 500 KM (250 euro )for each child, yet they provide little for children in terms of nutrition and professional care; that is a lot of money and it would be enough for a whole family to live on, but a family receives only 40-80 KM (20-40 euro ) (Social work manager, B&H).*

OECD (2006) reports that in some areas of education progress has been evident, but exploration of the issues around inclusion is still in its infancy, whilst UNICEF (2007, p. 13) reports that '*Separate provision for children with disabilities is still the rule*'. Even though there are moves towards inclusive education on the level of policies, in practice there is much debate about whether this is integration and whether it is the best educational option for children. Similar issues are raised in developed countries (Booth & Ainscow, 1998). There is, however, a general agreement among educationalists that all children should have equal access and rights to education but whether that will be fulfilled through special or inclusive education is still a subject for debate (UNICEF, 2007). The problem identified in this research is that integration and inclusion seems to be understood as appropriate for some groups of children and not for others. The informants expressed opinion that inclusion is more problematic for those with moderate and severe intellectual disability, for example:

*The majority of professionals declaratively support inclusive education. However, when asked, they list a number of reasons why all children cannot be included, especially children with more severe intellectual disabilities. They believe that for children with disabilities, being with others like themselves is the best option educationally and emotionally' (B&H, government policy maker).*

The professional practice frequently mentioned in literature on Eastern Europe in relation to education of children with disabilities is defectology (UNICEF, 2005, 2007; OECD 2009) and the next section will analyse this practice.

#### 6.1.1 THE ROLE AND FUTURE OF DEFECTOLOGY IN B&H AND BULGARIA

Traditionally in B&H and Bulgaria defectologists were responsible for the education and rehabilitation of children with special needs. The inclusion agenda, which is relatively new for this region, brought about new developments and requirements for

different professional profiles. As discussed in chapter two defectology is presented in the literature as the discipline responsible for segregating disabled children, and imposing strict medical approaches. In addition when planning the inclusion of disabled children there is no discussion of how defectology can be involved. However, closer inspection during this research revealed defectology to be relevant and influential in the rehabilitation and treatment of children with disabilities in Eastern Europe. Recognising this gap in the literature and a lack of regard for defectology in the process of reforms, this research looked into theory and practice around defectology. When talking about inclusion in education, a majority of the participants in B&H referred to the professional role of defectologists because of their expertise and understanding of impairments. However the views of defectologists towards inclusion are far from uniform whilst at the same time the discipline is currently undergoing significant change, especially in Bulgaria.

The reform of special education, involving changes in defectology, that took place in the 1990s in Bulgaria was discussed in chapter two and the effects of this reform were reflected throughout the interviews with professionals in Bulgaria. For example, younger informants in Bulgaria hardly knew anything about this discipline and did not use the word defectology. This is how one younger informant responded to a question about defectology: *'Before, it used to be a separate area of expertise "Defectology" and I think that speech therapy was only one of the branches in it. But right now I am not quite sure whether it is separated or what happened to defectology'*. Another, younger participant, knew a bit more, but again was not able to provide precise answers to the current status of defectology in Bulgaria. However, mid-career professionals in Bulgaria

sometimes referred to defectology when talking about practices around disability.

When asked about teaching of defectology and if it is finished in Bulgaria one informant, a university professor explained: *'Yes, it is finished at university where I am teaching, we have defectology, but this is the last group of students. I think the idea is that they will be trainers for resource teachers'*.

In B&H, however, defectology is still an influential discipline, and the majority of informants were not critical of defectology, nor did they present defectology as a problem. Instead, they presented the lack of trained defectologists as an obstacle to inclusion. This finding stands strongly in contrast to literature on this topic (UNICEF, 2005, 2007). Most of the participants talked about defectologists as a resource and the professionals who are most equipped to work with children with special needs. For example, in order to support educational reform and inclusion in B&H the government launched a program of mobile teams, where defectologists have the central role in providing consultation to mainstream teachers and supporting the inclusion of disabled children in mainstream classes (UNICEF, 2010). Initially this program was seen as a low cost and effective solution. A theme that was very prominent among B&H participants was that defectologists have a crucial role in supporting inclusion. In fact as soon as inclusion appeared to be an option in education, people turned to defectologists for support and advice. Furthermore the majority of defectologists who took part in this study expressed firm beliefs that inclusion comes under the remit of defectologists.



Defectology is composed of five sub specializations which deal respectively with intellectual disabilities, physical disabilities, partial and complete blindness, hearing difficulties and speech difficulties (Handicap International, 2004). Defectologists are specialised to work in these five different areas of disability. However one participant in B&H, a defectologist himself, raised his concerns that specialist defectologists can not address an array of impairments:

*For example as a defectologist in a mobile team, I can come twice a week to a school that has five children with different impairments, one with visual impairment, one with hearing impairment, two with mental retardation and one with behavioural problems. How can I adequately address all these issues?...*

Also, a few years after the implementation of this programme, un-anticipated issues emerged related to the work of mobile teams, as mentioned by the informants in this research. Firstly there are some practical aspects. In B&H 'mobile teams' are supposed to visit schools and provide support to mainstream teachers and individual children, especially with the development and implementation of individual education plans. However, difficulties with the operation have been noted by a B&H informant from the NGO sector: *'Either they don't have a car to go to schools, or a mobile team consists of one person. Furthermore the purpose of mobile teams to facilitate inclusion has been questioned because they usually work with the disabled child separately'*.

Also several tensions emerged when participants discussed defectology and inclusion. Some informants voiced their dilemmas about the role and place of defectology in inclusion: *'Educational inclusion must be the issue of pedagogy and not defectology,*

*psychology, medicine or sociology. Pedagogy is the discipline that needs to give answers to the problems of inclusion and decide how other disciplines will be involved' (Policy maker, B&H).*

In addition, several participants raised questions as to what extent the philosophical approach of defectologists can support inclusion...

*Defectologists, as educated today at our University in Tuzla are more medically oriented. Little attention is given to didactics and teaching methods, and I can see it from these young graduates that start working here. I think the old system of defectology training was better because it gave more attention to a didactic-pedagogic approach to a child...still neither is appropriate for inclusion. Defectologists cannot work as a defectologist in inclusion; this has to be done by teachers who take postgraduate studies and become specialists in the field...' (Defectologist- special school B&H).*

This introduces dilemmas about the future of defectology and inclusion.

The majority informants in B&H talked about defectologists as the most competent in addressing disability issues, however it emerged that different professions are beginning to take on their respective roles in inclusion. To what extent this complements defectology remains to be seen, as these practices are developing. It appeared that defectologists were not feeling threatened that their profession might become marginalised nor concerned that services will cease to require defectologists. Furthermore, they seemed to be unaffected or unaware of strong criticism in foreign literature. Still, there was one defectologist in B&H who voiced concern about the future of defectology:

*There is something that I call the watering down of defectology...because defectology is currently being adopted by other complementary disciplines, especially pedagogy which shows lots of interest in children with special needs. Now in B&H there is a postgraduate course in special needs. However the big problem is that this course is taken by people who did not graduate from complementary professions, so you have a person taking this postgraduate course who did English language studies. If you compare a defectologist with someone who studied English language you will see that*

*there is a huge difference. That person doesn't have knowledge in medicine, psychology, psychiatry and other disciplines important for defectology and work with children with special needs'.*

Those who took part in international exchanges stressed how different defectology is from special education in the West. Unlike other professionals they were more critical of special education in other countries and believed that the discipline of defectology has a place in the disability field:

*Whenever I have had contacts abroad, I realised that my work is not clear to them. They say you are a doctor and a teacher at the same time... Our system is very specific and our experts have a different education from those experts from the West... I think that we do something better, especially individual work with the child... colleagues from Slovenia and some colleagues from Germany were impressed when they saw some aspects of our work (Defectologist and policy maker, B&H).*

All defectologists who took part in the study stressed how important is to achieve progress with disabled children. One informant reflected on work with disabled children in the Region and in the West.

*We are a more eastern school, and the difference is that the eastern school is more focused on what a child cannot do and we try to improve that. In the west they work according to the social model, and they accept, sometimes too early in our opinion, the limits of that child. For example we get a chance to teach a child to walk at the age of seven, while somewhere else they would already get a wheelchair... we move these limits a bit more... (Defectologist and policy maker, B&H).*

This research shows that defectologists now work in various settings such as residential homes, special school and special classes in mainstream schools. In B&H defectologists are increasingly seen as facilitators of educational inclusion, through their work in mobile teams. There are also defectologists who work in community centres such as NGOs and day centres, and they are the people who actively work on

supporting educational inclusion. These findings challenge views encountered in the literature that portrays defectology as a discipline responsible for segregation (Des Power & Blatch, 2004; UNICEF, 2005). Even though defectologists have been somewhat responsible for encouraging segregation, it is worth noting that they are now making serious attempts to take part in inclusion initiatives. There has been some recognition that the name defectology is inappropriate and in the last few years attempts are made to address this. For example previously known faculties of defectology are increasingly being renamed in faculties for education and rehabilitation and defectologists into special pedagogues.

Arguably, then, defectologists can have a place in special education and inclusion, but their training and practice needs to be examined and reformed in line with the social inclusion agenda. For now, the Faculty of Education in Tuzla in B&H still has a very medically oriented curriculum without much of a social component (University of Tuzla, 2007). Efforts to explore defectology further could help in bringing practices in Eastern Europe more in line with human rights and the social inclusion oriented approaches. This could also improve our knowledge of how this discipline is changing and provide important insights into the professional roles necessary for building more inclusive societies. This research shows that defectologists can be supported to follow trends in inclusion if efforts are put into re-designing education in defectology and systematically including defectologists. However defectology is not the only profession that needs to be equipped to respond to the inclusion agenda, and the next section looks into the role of social workers.

As discussed in chapter two, social work developed differently in B&H and Bulgaria, influenced by different styles of communist regimes. In Bulgaria, during communism, there was a denial that social problems existed, whilst social work was deemed an unsuitable activity. USAID (2008) claims that the emergence of the social work profession and many of the community-based services in Bulgaria have developed as a response to the movement to de-institutionalize children in vulnerable situations. In B&H the social work profession was recognized as important in combating social problems back in the 1950s. Right now, legislation in B&H provides a vision for family support services including outreach, psychosocial counselling and mediation, but lack of resources to pay salaries, let alone benefits to clients, makes social work difficult (USAID, 2008). Centres for social work in B&H are severely understaffed, with most of the centres operating at half of the legally required staffing levels (UNICEF, 2003; UNDP, 2007b, 2008).

This situation was borne out by this study and most of the participants criticized the work of social workers in both countries. Sometimes the criticisms were not centred on the way social workers perform their duties, but more on the lack of resources available to them, poor premises and understaffing. The centres for social work in both B&H and Bulgaria are poorly equipped, whilst staff frequently do not have access to computers or are not trained to work with computers. A participant in an international organisation in Bulgaria formulated it as follows:

*The social worker's job is at the bottom of the helping professions. Supporting jobs are not well recognised by the state, not well paid, and there is a huge turnover in the child protection department because of very low payments and salaries and there is a recognition that it has to change.*

A social work manager in B&H, however, stressed that how much social workers will be able to provide depends a lot on the development of the municipality and municipal budgets. This participant also talked about the practice of outreach work in B&H:

*According to the law on social care the outreach work is obligatory... Our municipality has 18,000 citizens and so it is easy for us to control the situation in the field. We regularly go into the field and monitor the situation and provide interventions accordingly.... (Social work manager, B&H).*

The less optimistic view is provided a UNDP (2008) report that analyzed the situation in the social protection system in B&H. According to this report, social assistance usually consists of means tested cash benefits to vulnerable families, in the form of child allowance and different types of family allowances. In addition, however, UNDP (2008) gives examples of understaffed and poorly equipped centres for social work across B&H, some without IT equipment, unable to respond adequately to the needs of citizens. UNDP also claims that social work centres do not collect or analyze data on the social needs of the population, while citizens are not informed about their rights or criteria for claiming.

Parents and NGO workers stressed that social workers are mostly concerned with the administrative nature of their work with a focus on financial benefits. Even though social workers reported that their job is to go into families and conduct assessments, as reported in chapter four, parents say they do not receive any individualised services.

The majority of participants agreed that the social work profession is not supported by adequate resources as explained by a participant from an international organisation in Bulgaria:

*Social workers are people who keep documentation in Bulgaria. They don't do social work; no one pays them to do that. They have no money for mobile phones, or for transportation; no one expects them to go and see the clients, people they provide services to, so they just stay in one office, talk on the phone to different... you know clerks... and that is everything they do.*

Even though in one part of B&H (in the Federation of B&H) social workers at least administer larger cash benefits than before, the role of social workers appears to be very problematic. To what extent social workers can support inclusion in current circumstances, it is difficult to say. The job of social worker seems to be undermined by poor working conditions and low salaries. In addition decisions about disabled children are mostly made by categorisation expert commissions, psychologists, medical doctors and defectologists. It seems that currently social workers offer very little to clients, especially if they are employed in government social work centres.

The above findings are in line with the comments by Stubbs (1999) who criticizes the approach of social workers in B&H, because instead of challenging oppression and working with individuals, groups and communities they follow pathologising individualistic frameworks dominated by psychologists and defectologists. According to Stubbs, the true community development social workers in B&H are human rights activists and workers in women's groups, rather than those with a diploma in social work. The role of the latter group is primarily one of administrative relief of poverty,

individualistic work and being servants to psychologists (Stubbs, 1999, p. 26).

However, while others criticized their work, social workers themselves talked positively about their practices. Their concern was a lack of resources that they have available to distribute to families, but not the approach they adopt in fulfilling the needs and rights of disabled children. Still it appears that social workers do not have a clear vision of inclusion and, as Stubbs claims, they work without challenging old oppressions, one of which is the categorizations commissions. According to a manager in social care centre in B&H, the categorisation commission has the final word on what provision and services will be made available for the disabled child: *'Only with the categorisation document made by that commission can a child exercise certain rights in respect to social care'*.

#### 6.2.1 CATEGORISATION COMMISSION/DISABILITY ASSESSMENTS

Services that can strongly influence the lives of disabled children and adults are disability assessments boards, or categorisation commissions, as they are traditionally known in B&H and Bulgaria. Categorisation commissions can be defined as official bodies performing disability assessments and are a very important link in a chain of social and medical administration addressing disability in B&H and Bulgaria. In B&H the 'Commission for Categorisations and Assessment on the Competence of People with Difficulties in Development' is established on cantonal level or the level of Republika Srpska and it assesses capacities of people with disabilities according to its criteria (OECD, 2006). The commission usually consists of a paediatrician, a clinical psychologist or neuro-psychiatrist, a social worker, a defectologist and a medical doctor specialising in a particular impairment (an ophthalmologist or a hearing



specialist). In the literature on disability in the region, the categorisation commissions are often described in a negative light and blamed for putting children into specialised institutions (OECD, 2007).

The commissions are only bodies that can legally confirm disability status and percentage of disability, which is a basis for claiming social benefits, educational support or a disability allowance and pension. In Federation of B&H disability assessment of children is conducted on a cantonal level and in Republika Srpska on a municipal level. Assessments are conducted by professional commission consisting of medical doctor of different specialisation (depending on impairment), social worker, defectologist of particular subspecialisation and psychologist. All members of commission do their assessment and then produce one document with main findings and opinions, which is done on the basis of International Clarification of Diseases-ICD-10 (Cuk, 2007). One of the major problems with categorisation commission lays in the fact that it gives the percentage of disability on the basis of which benefits are calculated, but this often does not reflect the real needs of a disabled adult or a child.

In Bulgaria, categorisation is done by regional medical psychological commissions, attached to resource centres. In order to make assessments more educationally relevant Bulgaria created Complex Pedagogical Assessment Teams (CPAT) in 28 regional structures of the Ministry of Education and Science – the Regional Inspectorates of Education (RIE). Parents have the right to be involved in the assessment. According to OECD (2007) these are still constituted along traditional medical/defectology lines. The

Bulgarian Helsinki Committee (2002) reports that in Bulgaria children are easily placed in special schools, even children who have minor educational difficulties. Furthermore the Bulgarian Helsinki Committee reveals a case of a psychiatrist who was unaware that children with moderate and severe learning disabilities are not considered uneducable according to new regulations and that these children can be placed in special schools.

One participant working on children's rights commented on categorisation commissions:

*Parents cannot claim social benefits for their child unless they have a categorisation document as a proof. In our state everything has to be supported by papers. That administrative apparatus is extremely powerful. People in the centre for social work want their position to be covered by seeing appropriate documentation before they approve benefits. For them it is not enough to see a child, they have to see the categorisation paper. Even when they finish school, whilst waiting for employment they have to have categorisation again in order to claim benefits. Therefore everything starts with the assessment of psycho-social abilities of the child (NGO policy maker, B&H).*

Another problem reported by professionals is that mistakes in assessments do happen and they can have serious consequences, such as recommending the placement of a child in an institution. Once categorised, re-assessments are rarely done and changing the original disability assessment is a difficult administrative procedure.

*...regulations for categorisation are not used in some places, because we don't have enough psychologists to assess a child properly. There are not enough defectologists who will write a diagnosis....I am under the impression that professionals in these commissions use tests for the normal population, trying to find ad hoc solutions for the disabled child (NGO policy maker, B&H).*

There was a strong recognition among participants that the work of categorisation commissions is currently problematic and in need of reform. The difficulty is that in B&H there is no consensus on a definition of disability, so disabled people are differently defined in different legal documents, which then affects their entitlements (IBHI, 2007). OECD (2007) recommends that efforts be made to work directly with the Commissions or Boards. This would inform them of the requirements and to improve assessment and gate keeping practices aimed at preventing the placement of children with special needs in institutions or special schools in the first place. Furthermore, as mentioned in the introduction, the OECD has developed a cross national classification which will assign children to one of three categories A- disabilities, B-difficulties, C-disadvantage (OECD, 2009).

An example of positive change in carrying out assessments is the efforts made by the special school, Vladimir Nazor, in Sarajevo. This school is trying to make the testing of children with disabilities more accurate, but also less stressful and more family friendly. Now parents can stay with their children in the school over the several days that it takes for tests to be carried out. However, they have to pay for their accommodation which is the downside of this positive initiative. Social workers and NGOs are very eager to recommend this service and they argue that more centres like this should be opened. Unfortunately, however, the assessment made by this centre is not legally valid and it is only taken as a recommendation.

The categorization commission is a legacy of the old system, a body operating under the medical model and seen as undermining inclusion. The way a categorisation commission works perpetuates the approach where disabled children's lives are dominated by professionals. The examples given above show that categorization commissions do little to support inclusion. When assessing disabled children these commissions assess individual impairments, disregarding obstacles in society, or interaction between disabled people and environments. They do nothing to challenge traditional oppressions. In addition to traditional services, new types of services are being developed in both countries and the next section looks deeper into these new developments with the aim of bringing to light how much these support social inclusion of children with disabilities.

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### 6.3 TOWARDS COMMUNITY CARE

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There is a unanimous agreement in international childcare policy that community services offer a better and more humane approach to the care of disabled children than large residential institutions (Mansell, 2006). Policy analysis in the Region also usually argues for a move from large institutional care towards community care as the preferred option (Save the Children, 2003; UNICEF 2005, 2007; European Commission 2009). In 2005 UNICEF reports that even though institutional care is still the dominant approach, new forms of care are starting to take place in the region. In the course of the present study I identified and visited places considered to be delivering community services and alternatives to institutional care. The services singled out as

the most popular and desired by parents are day centres and these will be presented first, followed by other services.

#### 6.3.1 DAY CENTRES

In B&H and Bulgaria day centres are considered to be a type of service that can greatly contribute towards changing care for disabled children from segregated towards inclusive models. The number of centres, however, and financing are currently very different in B&H and Bulgaria. According to the IBHI (2007) study on disability policy there are numerous day centres in the cantons and municipalities of B&H, however participants in this study mentioned only nine day centres that offer a regular service. Official day centres are: Los Rosales Mostar, Sunce Pale, Day centre in special school Vladimir Nazor Sarajevo, Kuca Nade Odzak, Duga Novi Travnik, Day centre Maglaj, a day centre in a special primary school in Zenica, and Koraci Nade Tuzla. However the participants claimed that most disability associations provide some type of day activities, so unofficially there are many more places providing some form of day centre services. Just within the network of SUMERO (Union of Organisations for Support to Persons with Intellectual Disabilities in Federation of Bosnia and Herzegovina) there are fifty associations that provide some kind of day service for its users.

In B&H day centres are built and equipped by international NGOs or foreign donors, who train staff in the initial phase. Day centres provide day care for children and youths with physical and intellectual disabilities. This includes providing meals during

the time children spend in the centres, education, therapy and socialisation.

Continuing support for day centres depends on cantonal or municipal budgets. Few centres have become part of social work activities and most are financed on a project basis or sporadically by municipality funds. The status of the day centres in B&H is not resolved in legislation, whilst financing is highly problematic. Unlike B&H, in Bulgaria the day centres are recognised as official services with extensive resources invested in their development and in Bulgaria the day centres were a very prominent theme throughout the research. Government officials present them as their effort towards de-institutionalisation and bringing practices closer to the European Union. Parents on the other hand praised day centres as the only place that offers them something useful and a place where they feel their child is safe. Some parents also said that they noticed progress in their children's development once they enrolled in a day centre.

In Bulgaria day centres became more prominent in the pre-accession and accession stage when Bulgaria was required to show progress in social policies for disabled children. Initially this left the impression that community centres were only introduced recently with the EU accession projects. However, as explained by one NGO worker Bulgaria started to move towards community care long before the EU accession. This informant explained that the Irishman John O' Gorman, prominent in the de-institutionalizing movement in Ireland, came to Bulgaria in 1993 and encouraged and supported parents to start the first day centres, using the premises of disused kindergartens. As explained by this informant, at the time the government was not

interested at all. This shows that community initiatives were present on a smaller scale but a lack of proper support meant it did not generate bigger social change.

The participants who worked in day centres and rehabilitation centres in Bulgaria talked about accessing funds and achieving the status of official service provider through a popular EU/government initiative of outsourcing. An NGO needs to go through a rigorous licensing procedure and fulfil standards related to premises, staff, and financing in order to obtain a service provider license and win a contract for 3-5 years. The programme of outsourcing is very popular and well received as it provides an alternative to government run services, but the problem is that the contracts are not guaranteed. For example one NGO can invest significant resources and efforts to start a day centre and win the contract in the first place, but then on the next tender in 3-5 years this job can be taken away from them by a different service provider. According to Bulgarian informants NGOs would like to have some sort of guarantee that their contract will be automatically extended if municipality and service users are satisfied with the service. However they are aware this is against EU regulations.

Professionals from the day centres in Bulgaria strongly emphasised that centres are not another form of institutionalisation and they work hard in integrating these centres in the community. The professionals from the centres said that parents sometimes get the wrong idea that the centre will replace institutional care and this is what they are trying to avoid. So apart from taking the child home every day, they make sure parents are included in the activities and aware of progress. In addition they make efforts to

integrate children who attend day centres into mainstream schools or special schools. Even though day centres are not as developed in B&H, a similar attitude was encountered in Centre Koraci Nade (*Steps of Hope*) in Tuzla. This centre emphasises the social model and inclusion, with activities aimed at the promotion of children's rights, rehabilitation and socialisation, and integration of disabled children into mainstream schools. It also provides education for parents in order to equip them for the role of co-therapist. The centre works closely with the Faculty of Defectology in Tuzla, which organises some of their practical teaching and provides student volunteers for the centre.

The atmosphere in day centres was very different to that in residential institutions. Firstly the day centres are situated in towns in densely populated residential areas. In addition, day centres looked like any other school or pre-school place, with staff much more informal than in residential special schools and residential homes. The participants in Bulgaria were full of praise for the day centres since they allow parents and children to access different services, such as rehabilitation and logoped (speech therapy) services in one place, whilst providing day care at the same time. Another reason why day care centres are seen to be popular is because of service quality and better and more effective utilisation of resources. A majority of participants agreed that day centres provide an alternative to institutionalisation and serve as a vehicle for social inclusion.



### 6.3.2 SERVICES PROVIDED BY PARENTS' ASSOCIATIONS

Official day centres sometimes developed from parents' associations, but this research also identified a diversity of unofficial community services provided within parents' associations in both countries. For example, due to a lack of professional expertise on autism, parents of children with autism in Bulgaria developed their own services, as well as knowledge and skills on autism, as this was the only way to address the needs of their children. According to informants from this centre they had to develop specialised services within their association, as most of the centres for children with disabilities are not willing to accept children with autism because of challenging behaviour. Instead of waiting for the government to start a service in a difficult period of social and political transition, they took an old municipality building, renovated it, equipped and furnished it and now they are looking for ways to integrate their centre into the government's official activities.

The above example confirms the view that day centres started to develop within communities and some of the actions are clear examples of development projects and grassroots initiatives. This was also confirmed by participants from the parents' association in B&H. Since 1967 their association grew from one providing only humanitarian aid to one engaged with the community in producing sustainable social change. The work of parents associations confirms the view that projects in the community for care and support started to develop long before international influence demanded it. During the interview in one organisation, two managers, who are also parents of disabled children, gave numerous examples of the variety of their projects. Their approach was very systematic, starting with needs assessment in the community.

Unlike government centres for social work they developed a data base containing the needs of families with disabled children. As they say: *'Considering that we are parents ourselves we knew what a family needs'*. With their assessment they confirmed the urgency of addressing the needs of pre-school age children with intellectual disability and that is one of their projects. This organisation went on to develop different activities for parents, disabled children and adults. They also started to increase their advocacy activities in addressing the rights of people with intellectual disability. They currently work with various international organisations, but also motivated the municipality to give them support. They came up with an original and profitable employment strategy for disabled young people, as explained by the organisation manager:

*We thought that schools and preschools are not equipped enough. So we decided to go for ecological toys and learning materials. There is expensive equipment imported from abroad; nobody produces that here, so we started producing those toys with natural paint and materials.*

It has been noted that the approach to the employment of a person with an intellectual disability in parents' associations and day centres is very different to that found in traditional residential care and special schools. While special schools and residential institutions view the work of intellectually disabled people as a labour without market value, as discussed in chapter five, parents and staff in community centres are keen to develop commercially valued employment opportunities for intellectually disabled young people. In addition they reversed attitudes so that products should be viewed as having a higher value if they are made by intellectually disabled people, instead of being devalued and promoted as a charity:

*This is still an experimental workshop, we are not a company and we cannot be very profitable. They cannot produce so many of these products, everything is handmade. Every product goes through the hands of a person with mental retardation, and that gives the value to the product (Vesna, mother and parents' centre manager, B&H).*

### 6.3.3 PERSONAL ASSISTANCE AND FOSTER CARE

As reported by participants in B&H and Bulgaria, personal assistance is a service that can enhance social inclusion, supporting disabled adults in being independent, whilst for families with disabled children it helps permit parents to work and do other things, apart from providing care. In B&H personal assistance it is still in its infancy and only a small number of people receive this service, but it is something that the NGO sector strongly advocates for. Right now personal assistance is run on a project basis and it still has not been taken up as a national policy approach. According to research by International Bureau for Humanitarian Issues (IBHI, 2007) personal assistance is provided in both the Federation of B&H and Republika Srpska but to a limited extent. Altogether 18 organisations provide personal assistance services, which includes help with personal care at home and with going out. There is no data on the number of users covered by these services. It is important to note that parents of disabled children can take the role of carer, which in legislation is defined as 'care and help by the other person' and as such personal assistance extends to many more individuals.

The Bulgarian government policy makers said that personal assistance is a national programme supported in part by EU funds. At the time this research was carried out policy makers reported that personal assistance schemes covered 16,000 people from the national budget and 4,000 from the European budget. The policy makers said they

wanted to broaden the programme to give support to all families. One Bulgarian family that benefits from this program reported a great experience and said that personal assistance significantly improved the quality of their lives. However problems have been reported, too. For example, parents can only receive an allowance for personal assistance if they completely give up their job, as discussed in chapter four. Furthermore the service is unequally developed, as explained by a participant from an international organisation in Bulgaria:

*It is available in many municipalities, but not in all. Again, it depends on the municipality, if they want to develop it. There is no obligation on local government to provide the service. If the municipality wants they will do it. And this is what we want to change...we want government to ensure a minimum package of service.*

Also, all participants in this study agreed that foster care prevents the institutionalization of vulnerable children. According to Bulgarian government policy makers the government is developing foster care with at the present time 155 foster families in Bulgaria, of which 55 are professional foster families. However, according to the international charity Absolute Return for Kids foster care is undeveloped in Bulgaria with only 90 children in foster care placements (ARK, 2008). This view was supported by an informant from an international organisation: *'Nobody is working with the families. We don't have foster care developed at all; we have 80 foster families'*. Based on interviews and available data, this research shows that foster care is much more developed and more popular in B&H than in Bulgaria.

Informal types of foster care or kinship care have a long tradition in B&H, where children who lost parents remained with relatives instead of being sent to orphanages.

The development of foster care in B&H was supported by the presence of international organisations. Save the Children UK and UNICEF are the organisations best known for this work. According to the Policy on Protection of Children without Parental Care and Families at Risk in Bosnia and Herzegovina 2006-2016 (Ministry of Labour and Social Policy FB&H et al., 2006) there are about 1,400 children in B&H placed in foster families, mostly with relatives. Referring to figures from the 2005 document there are 805 children in FB&H, 500 children in RS, and 47 children in Brčko District. In Republika Srpska foster care is more widely used than other forms of placement (Ministry of Labour and Social Policy FB&H et al., 2006). This is encouraging, and foster care in B&H has the potential to replace institutional forms of care, but attention needs to be given to the following issues.

Foster care is very unequally developed across the country and a major problem is that foster parents in B&H rarely accept disabled children (UNICEF, 2003). However, there is evidence of change according to the informant in this study who works on foster care in B&H: *'Centres for social work in Tuzla Canton in (B&H) place disabled children in foster families in the city of Tuzla. Disabled children are placed in foster families in Tuzla and Sarajevo so that they can attend special schools there'*. Further research is needed to ascertain the extent of fostering of disabled children and to determine best practices, but the above claim indicates that situation maybe changed since 2003, when UNICEF's research was conducted.

Several problems with fostering practice are noted: the absence of standard procedures for recruitment, selection, training, support and supervision of foster families. Also funding and regular payments of cash benefits for the costs of meeting the needs of children placed in the foster families are different between the Federation of B&H and Republika Srpska, as well as between cantons (UNICEF, 2003). However, this research shows that unlike the biological parents of children with disabilities, foster parents are more likely to receive training in childcare, appropriate financial help, support from social workers and they can attend a foster care programme. The experiences of one foster family have been presented in chapter four. Being supported and equipped to care for a disabled child is also dependent on other available resources and factors. For example, the prevalence of fostering as kinship care means that cultural factors are important for the continuation and extension of fostering for disabled children. Fostering of disabled children needs to be promoted and developed in different parts of B&H by resourcing local NGOs and local centres for social work.

#### 6.4 CURRENT PRACTICES AND SERVICES –FOR OR AGAINST INCLUSION?

This chapter has looked at how current practices and services in B&H and Bulgaria contribute towards or obstruct social inclusion efforts. Davis (2005, p. 9) claims: *‘Central and Eastern Europe clearly has made tremendous progress in changing the policy and legal framework needed to transform the system of care in the region from residential to community-based...’*. The efforts to transform the services were identified, but the data obtained in this study in B&H and Bulgaria cannot support Davis’s claims that tremendous

progress has been made. Nevertheless it has been found that serious efforts are invested in developing inclusive education and new services, such as foster care and day centres. Community services, changes in social care and the launching of inclusive education are supposed to improve the inclusion of disabled children and their families and these services and new practices are starting to take shape in both countries. A majority of participants view day centres and community services as a way to facilitate social inclusion. In spite of numerous obstacles, this study indentified significant level of agreement amongst policy makers, frontline workers and especially families that this is the way forward.

On the other side little effort is being invested in training people working in existing services such as social and health care, special schools, or the categorisation commission to respond to inclusion agendas. In addition the practices identified as obstacles to inclusion were first and foremost the existence of large residential institutions, especially in Bulgaria and once a child is placed there society allows the failure to include. Many respondents, but not all, reported that special schools also act as an obstacle to inclusion. Others say that special schools are preparing disabled children for inclusion in society by equipping each child with various skills that will help him/her find and keep a job. They are aware that this is not the best approach. According to them, however, it is better than if the child sits alone and marginalized in a mainstream class with a teacher who is resentful because he has been given this responsibility, in spite of not being prepared to take on the task. Educational inclusion is not only problematic in Eastern Europe, and varying degrees of success have been reported worldwide (Booth & Ainscow, 1998; Armstrong, 2003, Florian, 2007). Still

inclusion is being talked about and used by professionals as a buzz word in both countries, but to what extent their work and current services respond to the inclusion agenda is highly debatable.

#### 6.4. 1 WHAT IS MISSING?

The participants prioritised several reasons as to why inclusion is not developing faster in B&H and Bulgaria. Among professionals, lack of resources was seen as the most important reason as to why greater social inclusion has not been achieved. They argued there are not enough social workers and teachers, whilst premises are not as well equipped as in developed western countries. Some even think that the new developments are creating confusion, as expressed by a medical doctor from B&H: *'If we compare the situation for persons with disabilities from 1995 to now only small improvements have been made. Organisationally the situation is worse than in 1991, but the expertise has improved'*. Also professionals in government services said their professions are underpaid and devalued by the society. These issues have not been reported by professionals in new community services. The professionals also said they lack opportunities to go abroad for professional exchange to learn how inclusion is implemented elsewhere. Those who had had the experience reported changes in their views on disability, as well as in their practice.

In addition there is a clear gap in provision of services. Both professionals and parents in B&H and Bulgaria stressed that early intervention services are missing and this presents a problem and undermines inclusion initiatives:



*As far as the age 0-3 is concerned there is a great gap in the Bulgarian system for the early intervention process and usually families go from one institution to another and they are looking for different kinds of help. Usually the Ministry of Health hasn't got the necessary infrastructure to work on this process so these families, which have children, are not provided with the proper care at such an early age at the moment' (Ana, mother, Bulgaria).*

Also the work of categorisation commissions, one of the most important elements in getting support, is bureaucratic and not child friendly with a strict focus on impairment. Another problem is that families receive little individualised service and support, whilst respite care opportunities are non-existent. The 'liveliness of the issues' around social inclusion is something to be kept high on the political agenda – it would be easy to sink under the task of changing/decommissioning institutions.

Additionally, several participants reported that traditional, as well as new services do not reach the most impoverished people. Little regard is given to people suffering multiple discrimination, for example disabled Roma children. There are no services in rural areas and disabled children's parents living in rural areas often do not know how to navigate their way through the maze of bureaucracy and how to fight for their children's rights, as explained by an informant from an international organisation in Bulgaria:

*In a day care centre you have people, how to say, who are on middle of the road. People of the middle class, who are knowledgeable, who know how to access services, who know their rights, and what the provisions are, but efforts on behalf of the state have not been made to access the most disadvantaged and actually these children from the most disadvantaged families will end up in residential institutions. This is something which needs to be addressed...*

Furthermore there is an important contradiction in inclusion efforts because the majority of new places developed to support inclusion are used only by disabled children. Even though these places prevent children being sent to residential care the question is how much do they support actual inclusion? We cannot say that children are included, if they stay in the community but spend most of the time only in the day centre with other disabled children and staff. Unfortunately limited initiatives are recorded where disabled and non disabled children play and learn together in the same day centres or kindergartens. This model is, to an extent, encountered in inclusive education, but it does not appear to extend to social inclusion as a whole. Policy makers and professionals in B&H and Bulgaria need to be clear what they mean by inclusion.

Inclusion efforts are also undermined by the environments in B&H and Bulgaria and the many features that act as forces against the inclusion of disabled children. These forces are noticeable straight away and can be listed in the following order: inaccessible environments, especially inaccessible public transport from the moment the child leaves the house and all the way to school; social services; public places like cinemas, theatres, supermarkets. In addition there are numerous structures which keep pointing to the importance of impairments, such as categorisation commissions, as well as rehabilitation experts who keep preparing and adjusting disabled children to fit mainstream environments.

Participants in both countries also talked about lack of awareness and knowledge of disability issues in society and the struggle to overcome the old exclusionary system.

Informants in both countries showed an awareness that existing practices are problematic in many ways. They frequently evoked issues of traditional training and the power of the medical model of disability. A perspective on how much could be improved if professional resources are increased was given by the informant from an international organisation in Bulgaria:

*In Mogilino [residential institution discussed in chapter five], we put an additional team of 24 people to work along with existing staff and these 24 people are rehabilitators, defectologists, some additional social workers, art therapists; and so there is an enormous development in the skills, in what children can do, their performance ... enormous; there is a paediatrician who visits them every week and looks after their diet and they put on quite a lot of weight.*

Finally even when resources are invested to develop services, there is no systematic evaluation to establish what programs and interventions support social inclusion and improve the quality of life of disabled children and their families. For example Panayotova (2009) argues that schemes aimed at independent living in Bulgaria are not monitored or evaluated and no impact assessments have been commissioned by the government, nor any reports made public. This approach has been encountered in B&H too (Maglajlic-Holicek & Residagic, 2007). As discussed in chapter one, being consulted and supported to participate is important in facilitating inclusion, but these practices have not been reported in B&H or in Bulgaria. Plans are usually made by professionals, without the participation of disabled people, whilst disabled children are usually not asked about their experiences.

#### 6.4.2 THE NEED FOR INCLUSION DEBATES AND A PHILOSOPHICAL SHIFT

This study reveals an absence of debates in B&H and Bulgaria on how professionals understand and experience inclusion policies and practices. Even though in Bulgaria a professional discussion on the role of defectology took place during the reform process it is hard to say to what extent professionals really accepted this philosophical shift.

*'The debates about commonalities and differences between defectology and special education, have been quickly brushed under the carpet, replaced by a more pressing preoccupation with the 'what, how and who' of inclusion and inclusive education'* (Tsokova & Becirevic, 2009, p. 395). In B&H everybody still accepts defectology as the discipline responsible for the education of children with special needs as well as inclusion, with, it seems no discussion as to its appropriateness. As noted previously in this chapter only a few professionals questioned the role of defectology in inclusion, whilst wide-spread discussion on disability models, inclusion philosophy, as well as a meaningful engagement with the children's rights agenda is almost completely absent.

Another important conceptual problem among professionals working in services for disabled children in B&H and Bulgaria is a complete disregard for the children's voice in planning and delivering interventions. The construction of disabled children as passive recipients of social and health care interventions, instead of active holders of rights, perpetuates social exclusion. How can we talk about inclusion and rights when disabled children are not asked where they want to live or go to school, and when disabled adults are denied the right to represent themselves? Professionals in government services and in NGOs who do not understand the inclusion principle, and

who focus on the child's impairments, further reinforce exclusionary practices and suggest that inclusion is too difficult to achieve.

Rhetorically the majority of professionals in this study did favour inclusion, but their understanding of inclusion seemed disconnected from empowering children; fulfilling children's rights; participation or addressing barriers in society; all prerequisites for achieving inclusion, as argued in chapter one. The responses of professionals interviewed corresponded to some extent with the normalisation principle. They expressed a belief that services need to be improved and that the lives of disabled children need to resemble the standard and form for non-disabled children, which is one of the postulates of the normalisation principle. Even though they talked about inclusion and rights, a majority of participants did not challenge the oppressive social climate, nor did they advocate for greater participation of disabled children and adults in decision making. The domination of disabled children's lives by decisions made on behalf of them by professionals is regarded as an acceptable state of affairs. This corresponds with Chappell's argument (1997, p. 4) that in the move towards community services, normalization legitimated the authority of professionals, without addressing power relationships between professionals and service users and disregarded economic and social contexts.

As argued in chapter one the social model gives a different perspective on disability and draws attention to exclusionary forces and barriers. However, interviews with professionals did not reflect discourse from within the social model. The prominent

discourse was that of the medical model whilst disabled children were viewed as in need of protection and professional help. After years of experience with various community services in the United Kingdom, Oliver and Barnes (1998) warn that these services, even when organised with the best intentions, frequently mean continuous domination of professionals over service delivery with little evidence of disabled people being involved in planning and delivery of these services. Reflecting on Eastern Europe Iarskaia-Smirnova (1999) argues that existing social institutions need to be humanised, while dismantling the old stereotypes that created rigid social structures.

Service providers have a crucial role to play in challenging the exclusion of disabled children and their parents (Middleton 1999; Clarke, 2006). Policy actions related to inclusion cannot be implemented if teachers, social worker and professionals in categorisation commissions are not supportive of inclusion. This chapter has shown that in B&H and Bulgaria inclusion ideas are not always well received. Resistance of special schools in Bulgaria, persistence of the individualistic medical model approach and bureaucracy are common features in how professional services operate in these two countries. At the same time, examples of grassroots' initiatives by parents and the modest but promising development of community care as such, is seen as an important transformation in general service provision. Professionals and services, however, do not operate in isolation, but are part of a wider social and economic climate in which disability is being constructed and addressed. This is debated in the next chapter on national and international disability politics.

## CHAPTER 7

# DILEMMAS AND TENSIONS OF INTERNATIONAL AND NATIONAL DISABILITY POLITICS

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The theme that loomed large throughout the whole study is that the disability and inclusion agenda in B&H and Bulgaria is deeply intertwined in the larger national and international context. According to Lendvai (2007, p. 28) South East Europe has a crowded international policy space and for over a decade now it has had a multi-level social policy governance, which was confirmed in this study. The aim of this chapter is to map the various influences in disability, inclusion and child care policies currently taking places in B&H and Bulgaria; to identify dilemmas and tensions that come with these influences and to suggest ways forward. Therefore the first part of this chapter maps the diverse international influences on the development of social and inclusion policies, whilst the second part presents contradictions and dilemmas that come with this diversity. Potentially problematic issues emerged after examining the use of exclusion/inclusion concepts, as well as the social model of disability in B&H and Bulgaria, as argued in the third part of this chapter. The final section suggests several ways forwards in advancing the inclusion of disabled children and their families.

## 7.1 CHANGING EXISTING DISABILITY POLITICS - DIVERSITY OF INFLUENCE

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As argued in chapter two in B&H and Bulgaria, political, economic and social transitions in the early nineties, the (1992-1995) war in B&H and recent drives towards EU integration, introduced the phenomenon of strong international influences (Deacon, 2000; UNICEF, 2003; Lendvai, 2004; Deacon & Stubbs, 2007; Saurugger & Radaelli, 2008). Currently the strongest pressure comes from the European Union and countries aspiring to join have to demonstrate progress in social reforms. As shown in chapter one, the EU in recent years has increased its attention paid to issues of social exclusion/inclusion, which affects member, as well as potential member states (Atkinson et al. 2005; UNDP, 2007; European Communities, 2010).

This research was conducted soon after Bulgaria became a full member of the EU. This timing provided an opportunity to discuss with participants the influence of the EU prior to accession and to consider its immediate effects on Bulgarian disability politics. This chapter, overall, is based on views of policy makers, activists and professionals directly involved with policy making or knowledgeable about policies. Those were informants from ministries, international organisations (IOs), international NGOs (INGOs) and national and local NGOs. They were asked if they thought that joining/ or aspiring to join the EU impacted on policies in their respective countries. The responses from the two countries varied significantly. Bulgaria experienced very strong pressures, prior to joining the EU, to demonstrate quick progress with social policies.



Before joining the EU Bulgaria was required to reduce the numbers of children and young people in residential institutions and special schools, and to develop policies for education and social inclusion of children and young people from ethnic minorities. One Bulgarian policy maker from an international organisation (IO) articulated these issues especially well<sup>7</sup>.

*In the pre-accession period Bulgaria was heavily criticized by the EU monitoring report on the conditions of children and people with disabilities and especially children and people living in institutions. At that time we almost had no community services and family support service and there was quite a pressure on government to start creating different alternatives.*

An issue that deserves attention, according to several Bulgarian participants, is that the EU funds are very difficult to administer. The EU style of working is new to government ministry staff and they are often unable to respond to calls for proposals or to access available funds. During this research it was found that even when funds were secured, sometimes due to a lack of human resources in a particular government agency, they were not spent. It transpired that resources were sometimes available, but relevant ministries lacked the staff and know how to start these projects. Another concern that was raised by the participants was that the EU requirements on child protection were not a high priority:

*... the whole pre accession was based on making the system aligned with the European Union and since child protection is a domestic issue it's not covered by the key areas and there weren't many specific requirements; it's not like the labour law where you*

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<sup>7</sup> Remarks from this participant are therefore used several times.

*have very specific requirement, or internal affairs that requires very specific legislative changes. Social policy is more open and considered as a domestic issue... (Policy maker, IO, Bulgaria).*

Furthermore, as a majority of participants discussed, the EU inclusion agenda is frequently misinterpreted by professionals in special schools and residential institutions in Bulgaria. Moreover there were occasions when inclusion strategies caused disputes among different policy makers and professionals on the ground, especially because the need to satisfy the EU requirements in Bulgaria was sometimes carried out in a great haste. The participants talked about situations where some residential homes were closed just temporarily to meet the EU demands, whilst children living in those institutions were transported in a rush without notice or explanation to another residential home. This corresponds to concerns raised in the literature by Bulgarian disability activists (Panayotova, 2009). The participants expressed the opinion that staff in residential homes felt threatened by closures and the prospect of losing their jobs. For example one school took the extreme step of frightening the children by telling them stories about how they would lose the only home they had. They also brought distressed children to protest in front of the Ministry of Social Policy to try to stop the closure of this school.

Nevertheless Bulgarian government policy makers confirmed their commitment and expressed political will for the policies of deinstitutionalisation, support for family, inclusion and the inclusive education of children with disabilities. Unlike participants from NGOs, INGOs and parents they offered official and optimistic versions of the

current development. This is interesting, because what happens on the ground in Bulgaria, especially in residential institutions, does not mirror this rhetoric. In addition government policy makers have never challenged or acknowledged the fact that elements of the inclusion agenda are difficult and unreasonably requested by outside organisations, such as the EU.

The participants in B&H had different views and a more relaxed attitude towards the EU policies than Bulgarian participants: *'The European Union should be our goal, but within our capacities...we need to be given the opportunity to slowly build society according to the EU standards, instead of just doing it for the sake of gaining membership'* (NGO worker, B&H). In B&H the major political ambition is EU membership, but the accession is not certain in the near future and so there is much less pressure than in Bulgaria. Whether they will have the same approach closer to the actual accession or rush into ad hoc solutions to satisfy the EU requirements remains to be seen. This research shows that the European Union is a major driver of the inclusion agenda in B&H and Bulgaria (Government of Bosnia and Herzegovina, 2009; Republic of Bulgaria, 2010). However, economic and political pressures that come from other powerful agents also influence inclusion in B&H and Bulgaria.

Supranational organisations and financial institutions such as the International Monetary Fund (IMF) and the World Bank (WB) have a very powerful role in shaping the future of welfare and social policies in both countries. In fact, political globalisation and the influence of major stakeholders such as the World Bank, tend to move policy

making away from a unified European Union model (Deacon, 2000). The works of Deacon, Hulse & Stubbs (1997) and Deacon and Stubbs (2007) draw attention to the importance of analysing the frequently competing influences of international agents in South East Europe. Numerous international organisation and international NGOs are involved in social policies and education, for example; Organisation for Economic Cooperation and Development (OECD), Organisation for Security and Cooperation in Europe (OSCE), United Nations Development Programme (UNDP), UNICEF, the Open Society Institute (formerly known as the SOROS Foundation), to name but a few. The role of the WB and the IMF Fund is different from other organisations and agencies, since they facilitate reforms by giving large sums in loans and credits which are conditional on specified criteria being met (Stubbs, 2007).

The World Bank declares its aim as fighting poverty and emphasises that disability and poverty go hand in hand (Braithwaite, et al., 2008). They claim to support inclusive development where disabled people and the parents of disabled children are encouraged to contribute economically and to move from benefits to full employment (World Bank, 2008, 2009). It is very questionable, however, as to what extent this can be achieved in countries facing high levels of unemployment like B&H and Bulgaria. This is especially the case since attitudes and views towards disability, as well as resources, are still at a level that does not permit implementation of these programs. If policies are only focused on labour productivity, excluding other means of support, like cash benefits, disabled children and their families will be pushed deeper into poverty and exclusion. However, a reduction of material support is exactly what the World Bank is arguing for, extending strong criticisms of the B&H government for spending too

much money on social protection cash transfers (World Bank, 2009). In Bulgaria the World Bank achieved this goal and cash benefits are reduced to a bare minimum (World Bank, 2008) something that the parents strongly objected to on the grounds that they need financial support to pay high care costs and there is still a lack of jobs.

More recently, in order to save stand-by arrangements with the IMF, B&H, gave in to requests to impose restrictions and savings on pensions, and disability benefits among others. The World Bank requests reductions of 10% in cash benefits before they approve large loans (Dnevni Avaz, 2009). In 2010 the IMF exerted even stronger pressure on B&H to reduce benefits and disability allowances for (1992-1995) war veterans. Even though these allowances are generous compared to allowances for people disabled for other reasons, this measure resulted in demonstrations and fierce political battles by the army veterans (Reuters, 2010).

Apart from supranational agencies, the diversity of influence also comes from various policy 'experts', discussed by Deacon et al., (2007) who argue that these people have an important place in shaping social policies, but their role is not addressed fully. These policy 'experts' were not interviewed for the research, however I am familiar with their work through professional networks and conferences. The issue was also raised by the research participants and it appeared that international workers, consultants, and experts are established as legitimate actors in policy making in the region:

*There were many consultants working here last year in the social area, the World Bank as well; we had a big program on child welfare reform and it was co funded by the EU, but the Japanese government as well and it was meant to bring in good examples... Actually the whole strategy was developed by external experts who worked with the government.... (Policy maker, international organisation, Bulgaria).*

Another significant influence in the social policy arena comes from international and national NGOs. With the promotion of social inclusion, NGOs in both countries found a place and role in providing community services or working on raising awareness about the human rights of persons with disabilities. During this research it emerged that NGOs play an important role in facilitating the inclusion of disabled children. They advocate for human and social rights, start alternative services and participate in policy making. There were, however, significant differences between local and international NGOs, and international organisations such as UNICEF, OSCE, OECD and Handicap International and their approach in advancing social inclusion.

It was clear that international NGOs (INGOs) and international organisations (IOs) have greater power and resources and are more prominent in influencing government policies than local and national NGOs. They participate in popular round table discussions and they commonly lead the development of plans and actions. INGOs are more focused on awareness raising, policy making and research, keeping away from direct service provision unless it is through partnership (funding and monitoring) of local and national NGOs. In addition they involve policy 'experts' mentioned previously who conduct research and publish policy reports, which are used by government as needs assessments. National disability NGOs, on the other hand, see

their role primarily as providers of services, with few engaged in disability activism. They often take part in policy making but have much less influence than INGOs and IOs. This reflects the tension between international and local agents, often influenced by an imbalance in financial and technical resources. There are occasions when these actions are complementary with large international organisations providing financing and support to national and local NGOs. Often though, these imbalances create tensions and an atmosphere where international experts and NGO workers impose their ideas without regard for, or willingness to support local knowledge.

#### 7.1.1 THE INFLUENCE OF THE DISABILITY AND CHILDREN'S RIGHTS AGENDA

At the time when this research was carried out the UN Convention on the Rights of Persons with Disabilities (2006) (UNCRPD) was gaining momentum around the world with many countries signing and ratifying the convention. As argued in chapter one, this convention is seen as a significant instrument in advancing inclusion. However, in 2007 and 2008 the convention still did not have a powerful influence in B&H and Bulgaria and it was hardly mentioned by participants as an instrument that had any relevance to national policies. Still, the disability rights activist in B&H who was present at the UN when the convention was discussed said:

*I had an opportunity to see how much the B&H delegation advocated for acceptance of the convention, especially the act concerning disabled children...however our country still has not signed let alone ratified the convention. ...and that is maybe the biggest problem. To be honest I do not know to what extent the country is ready for it. The standards rules have been adopted in 2003, but they are not obligatory. The convention is indeed obligatory and that is probably the reason why it still has not been signed (Disability activist, NGO, B&H).*

By 2010 the UN Convention on the Rights of Persons with Disabilities (2006) was signed by both B&H and Bulgaria. However it has been only ratified by B&H and this came after strong pressure by disabled peoples' organisations.

The United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (1993) were highlighted as the instrument that has contributed the most towards advancing the position of disabled people in B&H. Organisations of people with disabilities in B&H actively promoted these rules, so that in September 2003 they were adopted by the Council of Ministers of B&H as a document that needs to be used as a basis in policy making (Cehovic & Zahirovic, 2006). The UN Convention on the Rights of the Child (1989) was also mentioned, especially by IOs and INGOs, as a good basis in advancing inclusion. Both B&H and Bulgaria signed and ratified the UN Convention on the Rights of the Child (1989) but the rights of children, especially disabled children are too frequently violated, as highlighted throughout the thesis. This is especially the case with article 12 on child participation and evidence shows that this article is almost never observed. This can have grave consequences, especially if the state is considering placing a child in an institution:

*The Commission in Centres for Social Work decides whether a child will attend mainstream school or go to residential special school or an institution. In this situation a child is not really asked. The UN disability convention states that the opinion of the child will be considered in decisions regarding that child. I think it was in fact the suggestion of B&H to incorporate that article, but this is surely about children who have mental abilities preserved. We cannot expect from a child with mental retardation to decide where and how he/she will live and go to school... (Disability activist, NGO, B&H).*



As discussed in chapter one the statement above shows a strong relationship between the ways impairments are socially constructed and the implementation of rights. When it comes to disabled children, especially children with intellectual disabilities, a main postulate that 'rights apply to all children' seems to be forgotten. Furthermore there are misconceptions in applications of these rights. Professionals, even disability activists express opinions which can be interpreted as a social acceptance that human rights fulfilment depends on social conditions, good will and nature of the impairment.

Since rights are unconditional one would think that these violations would be recognised by the UN committee, supposed to monitor rights implementation, which would then instigate remedial actions. However, one Bulgarian activist talked about how this is not the case in practice and how organisations compete and misinform one another when it comes to UN committee hearings. According to this informant there are lobbies within the country, which want to present a particular picture and they try to exclude those who have different findings, especially those who are very critical of the situation in relation to children's rights. The usual procedure is that at the UN committee hearings the countries present a state report and an alternative report. The alternative report is usually compiled and finalised by an INGO that often takes the lead in doing so of its own accord. Information can be rather selective or they might not have a sufficiently nuanced picture of what is happening in particular areas, like disability for example. As argued so far, diverse influences, and the work of NGOs, INGOs and IOs, bring in new ideas and opportunities for inclusion. However throughout the study it emerged that the social inclusion field is also loaded with

tensions, dilemmas and contradictions and they will be further discussed in the next section.

## 7.2 CONTRADICTIONS, TENSIONS, DILEMMAS, AND THE SEARCH FOR A WELFARE MODEL

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Even though the EU and international agencies have the same broad inclusion agenda for the Region (UNICEF 2007; European Commission, 2009; OECD, 2009), implementation strategies on the ground vary significantly. As presented in chapter one financial support for parents of disabled children is necessary in overcoming exclusion and this has been also expressed by parents in chapter four. However policy makers in B&H and Bulgaria expressed completely different views on this. For example B&H, especially the Federation for B&H, is more inclined towards increasing financial assistance to families as specified in the Amendment of the Law on Social Care (Government of B&H, 2006). Bulgarian policy makers however, argued against this approach, claiming that increasing financial assistance will create dependency and foster poor productivity. Their policy approach is the provision of community services for children and employment for the parents. They maybe favour this policy approach because of the pressing need to overcome institutionalisation issues, but also because they have been exposed to closer scrutiny by the EU, IMF and the World Bank.

This is just one example of a contradictory approach in addressing inclusion in B&H and Bulgaria. Furthermore, when considering disability policies in Bulgaria, Panayotova (2009) argues that major changes are needed with policy measures which, formulated alongside the medical model, fail to take into account the problem of social exclusion. There are also unresolved issues in how changing welfare models reflect an inclusion agenda. Wagener (2002) argues that the communist welfare state was very different from the European (EU) model and that the countries of Central and Eastern Europe need to achieve the transformation of their political and economic system, including catching up with productivity levels. In communism, welfare was a worker's privilege rather than a citizen's right. In daily life, of course, the difference was minimal, since almost everybody was a worker. Wagener argues that the convergence of social conditions will be the outcome of economic convergence; it cannot be its precondition. Hence, candidate countries need to be free to choose welfare regimes which they think are appropriate for their stage of development and their social culture. However due to international pressures and loan conditionality, achieving this goal might be difficult.

In relation to disability, the Bulgarian system is now more oriented towards labour productivity and community services, avoiding cash benefits. The B&H social policy system was for many years exposed to a complex mix of humanitarian and security interventions which directly affected the processes of social and political change (Deacon & Stubbs, 2007). The transition from communism and socialism in B&H was different from the transition in other countries, since B&H was not exposed to what Stubbs (2008, p. 4) calls a 'shock therapy of neo-liberal adjustments'. Instead a

humanitarian approach for a long time dominated international influence. The effects of this influence are still felt and the needs of disabled people and children are often met through the works of humanitarian organisations. The image of humanitarian actions is not easy to shake off and there are those who still see NGOs and international organisations as organisations delivering humanitarian aid instead of being agents of political action and change. This is a difficult tension to resolve as humanitarian aid provides the cash and assistance to vulnerable families, but this relieves the state from responsibility and undermines a rights based approach.

However, the humanitarian approach in B&H is possibly acting as a buffer to the neo liberal agenda promoted by the World Bank in the Region. The World Bank advocates for privatization of health insurance and the promotion of productivity above social safety, which impacts unfavourably on disabled children and their families. With their neoliberal agenda the World Bank contradicts the EU social solidarity model (Deacon et al., 2007), which has a direct implication for the inclusion agenda. One of the participants in Bulgaria highlighted the contradiction between the inclusion rhetoric and the reduction in financial and human resources in social work centres. Institutions like social work centres, schools and community centres need to be strengthened to cater for the diversity of the population and this will require resources. Naomi Klein in her famous book *Shock Doctrine: The Rise of Disaster Capitalism* (2007) strongly criticizes the World Bank's neo-liberal ideology arguing that it destroys indigenous capacities and exacerbates poverty. Klein (2007) argues for a mixed economy where developing nations are not coerced by the developed Western nations who run the IMF and World

Bank, but are allowed to choose their economic destiny. However it is very unlikely that developing nations can resist these powers, because of pressing needs for funding.

Both Bulgaria and B&H are adjusting to a mixed economy of welfare, from the bureaucratic state collectivist system of welfare and state paternalism that dominated Eastern Europe (Deacon, 1992). With change still ongoing, it is not yet clear where on the Esping- Anderson (1990) classification: Scandinavian, Bismarckian, liberal or conservative, these countries fall. In addition there is a popular political rhetoric among policy makers in both countries that policies need to be adjusted to a 'Social European Model'. However they fail to acknowledge that there is no clear European Model, nor common understanding of what the characteristics of EU welfare in current member states are (Deacon & Stubbs, 2007). In addition it must not be forgotten that economic indicators in B&H and Bulgaria are much poorer than those of Germany, the UK, Italy or France and this inevitably reflects on welfare development indicating that the social model cannot be the same across Europe.

This brings up the next agenda in the development of social policies for disabled children and that is the relationship between the state, parents' and children's rights. This agenda is not being addressed in B&H and Bulgaria. In spite of a strong rhetoric on children's rights, it is by no means a radical liberationist agenda based on views that children need to be given complete freedom and the same rights as adults (Harding, 1991). The zeitgeist in both countries is that children need to be protected and cared for and it is parents who have the most power to decide the wellbeing of their children.

This, according to Harding (1991) reflects the social policy orientation where the state is supportive of birth family and parent's rights. This is a change from what it used to be like before, especially in Bulgaria, where the state assumed responsibility for disabled children in a network of residential institutions. Currently the state plays a part, but it is not a completely protectionist system where the state is quick to denounce the rights of parents, or interferes much with family life. However due to the large number of residential institutions and slow changes in the mentality of professionals and policy makers, Bulgaria is still trying to overcome a protectionist communist legacy. Furthermore in the old system there were no mechanisms to lobby for needs anonymously from below and welfare recipients were the object of provisions, but never active subjects in defining needs and running services (Deacon, 1992). This is something that needs to change in the minds of service providers, as well as the general public in both countries.

#### 7.2.1 POLICIES: TRANSFER, TRANSLATION OR A PROJECT?

The tensions and dilemmas around the social inclusion agenda also arise because of numerous examples of unsustainable, as well as unhelpful and contradictory strategies among different stakeholders. The research found that the national policy choices frequently sprung from individual projects, without due consideration for the capacities in receiving countries. Furthermore policy making in both countries is influenced by the actions of foreign NGOs, which often look for quick solutions from developed countries of the EU. For instance both B&H and Bulgarian participants said that they look for examples from abroad. It appeared that in Bulgaria, the UK was very

influential in bringing in new policies as commented on by a policy maker from an international organisation:

*.... in the UK you can do it as a pilot model and if it proves successful it will continue; in Bulgaria it doesn't matter if it is successful or not you have to change it in legislation. The model can be very good, but legislation takes time and then you've lost it.*

The presence of international agencies and foreign consultants in South East Europe (SEE) could be seen as encouraging policy transfer (Deacon et al., 2007). However Lendvai and Stubbs (2007) put forward the idea that the process of policy translation rather than policy transfer is more appropriate to describe policy processes in SEE. Policy translation is a more fluid and dynamic process where policies are not copied in their original form but are constituted by multiple actors, networks and policy brokers. Whether policy transition takes into consideration the fit with local conditions and sustainability, is not always clear. The policy makers were asked how they construct policies and whilst there were strong indications that they look for examples from abroad, the straightforward transfer does not happen:

*In policy making we usually look for examples from abroad. However, this usually shows that they cannot be applied directly here. I don't like the fact that we always try to translate policy making initiatives either from the region or from the West. We need to recognise that Sweden, Norway and the UK have much better standards when it comes to policy and practice so we cannot really copy them exactly (NGO worker and policy maker, B&H).*

It has been reported that the development of policies in the field of disability is increasingly conducted with the participation of disability activists, who are sometimes disabled people themselves or parents of disabled children. However their opinions

are not always respected as the mothers from parents' organisations reported. This was confirmed by a Bulgarian policy maker from INGO when asked if parents participate in policy making: *'On paper it's supposed to be. In practice it isn't really the case'*. In commenting on the currently popular model of development of strategies and plans of actions, government policy maker in B&H said: *'Those strategies are often the outcome of individual projects and are not based on assessment of the actual situation'*. This was also the case in Bulgaria, where parents and informants from INGOs and NGOs stressed that the needs of communities were not assessed and researched. This approach resulted in a situation where services in some towns have no users, whilst in Sofia for example there is a great demand but not enough day centres. Furthermore, Bulgarian parents and NGO workers claimed that research could establish what clients need and help in creating diverse services, instead of offering the same to everybody.

This may be related to government planning and the style of policy development. For example policy makers did not talk about policy cycles, which is a commonly accepted approach within the field of policy making (Young & Quinn, 2002) nor developing policies based on assessment, policy proposals, implementation strategies and evaluation. Also it emerged that domestic policy makers are unsure how to carry out the process of harmonising national legislation with the EU legislation. One policy maker said that these processes are very unclear to domestic stakeholders, who look for similar laws and regulations in other countries, but then the problem is that these are not readily available. What usually happens is that international agencies put on strong pressure on government ministries, bring in their experts, engage NGOs and provide injection of funds for solutions to be accepted. This results in a situation where



policies or strategies are not embraced by all stakeholders, with some refusing to take these new developments on board. In addition participants in both countries argued that these policy documents are loaded with messages about children's rights, equality and non discrimination, but lack implementation and enforcement mechanisms, as commented on by a Bulgarian policy maker from an international organisation:

*In Bulgaria, in order to be implemented, policy or strategy has to be transformed in legislation. I did an assessment of all policies concerning children and their rights and there were 22 of them; there was strategy for children with disability, for street children, for children in institutions, I mean everything that you can think of. None of them was budgeted for and frankly, very few of the measures were really implemented.*

Several practitioners claimed that the parents of disabled children advocate for the individual needs of their child, even if they are politically strong, instead of using their experience to advocate for all disabled children. These claims are however contradicted with examples of parents' activism in both countries. Parent organisations were highly praised by parents and it is sometimes the only place where parents and children get much needed support. In fact parent organisations are becoming increasingly recognized by professionals themselves, as communicated by this defectologist in

B&H:

*You need to visit parent associations here; they are very transparent, they are doing a great job, I can only congratulate them...After all they are parents of those children. Imagine what a defeat that is for our profession, when a parent association shows better quality in certain jobs than defectologists do. That is like some kind of deterioration of defectology...(Defectologist from special school, B&H).*

Overall it transpired that policy making does not reflect an inclusive approach and that children are never asked what they think about policies and projects that are

developed for their 'benefit'. An important contradiction within social exclusion action is that it excludes the people and groups who are socially excluded from the debates and plans to tackle social exclusion, as discussed by Beresford and Wilson (1998 in Warren & Boxall, 2009). The situation may be slightly better for some groups such as Roma, and disabled adults, but disabled children are completely excluded from the discussion. This is especially the case for children who have intellectual impairments and/or those who do not use speech to communicate, as confirmed and debated in chapter three and five. This is in stark contradiction to inclusion philosophy where child participation is one of the main components. Another important factor in advancing inclusion and exposing barriers are NGOs and civil society. In the UK, disabled peoples' organisations have made a major impact on disability politics and policies (Barnes & Mercer, 2001; Oliver, 2004). This research however uncovered that in B&H and Bulgaria there are numerous problematic issues around the work of NGOs.

#### 7.2.2 NGOS AND INCLUSION

Even though NGOs occupy an important place in advancing inclusion, bringing in new practice and generating social change, this research identified various problems with their work. This research recognized that the position NGOs occupy is not clear in the current climate. They frequently have to compromise between struggling to keep their organisation going, increasing their profiles and providing services. Several participants in this study expressed doubt that NGOs are able to bring about social change and advance inclusion. One of the reasons for this doubt, as stressed in Bulgaria, is because most of the national and local NGOs are established with people who used to work in the old system, responsible for the exclusion of disabled children.

They are people who do understand why the system needs to be changed. Lack of professional capacities and the levels of people's knowledge have been also mentioned in the literature (see Maglajlic-Holicek & Residagic, 2007), as well as concern over financial transparency (DFID, 2005). The criticisms from the literature were reflected in interviews too. A government policy maker in B&H remarked:

*In B&H we have an 'aristocracy' of NGOs where around ten of them have a monopoly and they do not share information. When we cooperate the partners are individuals and not organisations...most of the resources are used on their expenses and travel. There are no mechanisms through which government can give support to disabled individuals through NGOs.*

These concerns raise an important question: whether NGOs do their job because they want to address disability issues and generate social change or whether they do it for the sake of securing employment for themselves? These problems are more acute in cultures burdened by poverty and inexperienced in civil society actions in general, as argued in chapter two. Issues have been acknowledged in the literature and NGOs in SEE have been criticized for following donors' agendas rather than the expressed needs of communities; for short term 'project cultures'; for an emphasis on building organisations instead of addressing social goals, and for distancing NGOs from grassroots activism (Stubbs, 2006). Major growth in the number of NGOs in the past 10 years has been related to the actions of international donors. These, according to Maglajlic-Holicek and Residagic (2007), stimulated the rise of NGOs which, instead of being truly civil organisations, now resemble a private business sector focused on absorbing donors' funds. Also experienced professionals from the social sector are excluded from working with the international NGOs if they do not speak English. Furthermore evaluations of the projects are frequently conducted without users'

participation (Maglajlic & Hodzic, 2005). In addition problems with monitoring the work of NGOs were mentioned in both countries, as commented on by one Bosnian participant: *'no-one is able now to monitor them to see what kind of quality they provide, what kind of capacities their services have'*.

With national and international NGOs becoming official and unofficial providers of services, the tensions about the quality of services have been highlighted too. In B&H professionals from government institutions expressed suspicions about the way some NGOs work and the services they provide, especially around independent living for disabled young people. In Bulgaria however NGOs were critical of the quality provided by government agencies:

*The quality of the services goes down after the municipality takes over. Unfortunately, the situation is that when the municipality starts to govern these NGO activities, they put in staff who are not so well qualified, but they put these people in because of their private relationships (NGO, Bulgaria).*

The actions of INGOs also introduce tensions and dilemmas and sometimes go against country policy objectives. At times they provide desired community services such as play groups, toy libraries, preschool services, mobility aids temporarily, thus creating a false impression of true improvement and change, with these unsustainable services. Furthermore different NGOs and donors work according to different agendas, sometimes not clearly thought through. The following quote illustrates this point:

*...British, French and German NGOs donated really enormous amounts of money to residential institutions ... and now after several years they see that everything is stolen or hidden and none of the toys or equipment they provided is used....because there are*

*no professionals, but they never, never think about the people...I say to them NO you should pay salaries, you should train people and never buy clothes, shoes, but that is the donor mentality, they continue to do that... (INGO worker, Bulgaria).*

The above also highlights the problem of corruption that has been raised by several participants in Bulgaria, who gave examples of misuse of donations by people who run homes for children. Another level of corruption is amongst officials and people in power who employ staff in child care centres and services not according to the knowledge of the staff but because of personal connections, as mentioned above. In addition allocation of government's funds to national and local NGOs, as expressed by both B&H and Bulgarian participants is not always done on the basis of the NGOs capacities, but on their good or bad relationship with particular ministers and personal lobbying. This is a low level of corruption compared to what is happening at the higher levels. In fact Bulgaria, was branded as the most corrupt of 27 members of the EU and was excluded from receiving 500 million euro in financing from the EU European funds in 2008 due to corruption (Castle, 2008).

This study has identified a patchwork of frequently contradictory government, IOs, INGOs, and national and local NGO initiatives in disability policies and practices. These contradictions sabotage a clear understanding of social inclusion and a radical example of confusion is that some stakeholders invest in improvement of residential care whilst others are struggling to close down as many residential care facilities as possible, all under the guise of the inclusion agenda. Some policy makers also advocate for the reduction of financial assistance, some for an increase, again all to improve the situation of families and children and advance inclusion. Apart from contradictions and dilemmas introduced by diverse agents, this study revealed that the

reason for many problems in taking inclusion forwards and translating policies into practice stem from negative social attitudes and the ways inclusion is understood or misunderstood.

### 7.3 ATTITUDES AND TRANSLATING EXCLUSION/INCLUSION AGENDA IN B&H AND BULGARIA

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Analysing the responses from both countries it became clear that negative social attitudes towards disability still prevail. It emerged strongly that twenty years after transition from communism, attitudes and social awareness about disability issues are changing, albeit too slowly. An NGO worker in Bulgaria expressed this in the following way:

*For me the biggest problem is the attitude which the community has towards these children. I think this is not because we are not a tolerant society, but because of this practice put in force years ago. The medical model is still in place. I hear that there is a lack of social activities with families in the hospitals and I heard there are still doctors who advise families to leave their child because it will be difficult.*

Even though B&H was a socialist country with a moderate form of communist ideology, as discussed in chapter two, it still lags behind western European countries in changing its culture and attitudes towards disabled people. This was reflected upon by a doctor in Sarajevo who was very critical of the prevailing culture in society regarding disabled people:

*When I just started to work as a neurologist I spent some time in Holland and there I saw lots of people with different impairments and in wheelchairs on the streets, which took me by surprise. It looked like they have many more disabled people compared to B&H, because disabled people in B&H were removed from society and placed in institutions. We do not see them on the streets and those we see are usually beggars which give a bad impression of them. There are not enough actions to sensitize the population and there is not enough pressure to change the situation.*

Still, examining the ways participants talked about attitudes it emerged that negative attitudes are discussed as an abstract phenomenon, almost something that nobody is directly responsible for. However the experiences of all the parents and children who took part in the study revealed this phenomenon as an unpleasant everyday reality. Mothers referred to their hurtful experiences in the playgrounds, shops and community settings, as well as the bullying of disabled children. They defined these negative social attitudes as a universal issue that causes hurt and distress. In addition mothers in Bulgaria mentioned very negative attitudes towards disabled children displayed in the media. When the Bulgarian government announced plans to build community housing for disabled children in one small town, the locals organised demonstrations that were televised. The parents said that this public display of prejudice and animosity towards their children was especially hurtful. One mother recalled: *'They were saying we know who gives birth to such sinful children...'* The idea that religious views impact negatively on acceptance has been explored in the literature and this is a reminder of how these views operate in different cultures (Cross, 1998). In addition non-acceptance of disability relates to the socio-cultural construction of disability as discussed in chapter two, and in B&H and Bulgaria negative constructions were strengthened by political ideology that denied the existence of difference.

Even though negative attitudes prevailed, the research identified attempts at awareness raising and barrier removal in both countries. For example in B&H some television programs include signing for deaf people and disability issues are increasingly being reported in the media. However these reports frequently contain charity messages or express pity towards disabled people, focusing on impairments or poverty, with little or no critique of cultures in society, barriers and prejudices. There are also more charitable actions by B&H and Bulgarian citizens who donate money, and old clothes, especially to residential care institutions and these actions are seen as an indicator that society is changing. This is very much in contrast to the social model of disability, which is very critical of the charity approach (Barnes, 1992). It is also contrary to the children's rights approach, which is based upon the premise that children have rights that need to be fulfilled not as a matter of charity, but as an obligation and responsibility of government and its institutions (Lansdown, 2005). Even though many participants blame negative attitudes for exclusion, the analysis of the situation in B&H and Bulgaria corresponds to what Barnes (1992, p. 5) argued when writing of UK society: *'the type of discrimination encountered by disabled people is not simply a question of individual prejudice, though this is a common view, it is institutionalised in the very fabric of our society'*.

Apart from negative attitudes in both B&H and Bulgaria, disabled children and adults are still very much excluded by inaccessible physical environments. The majority of participants were united in their responses that physical environments present a big obstacle, as discussed in chapter four from the perspectives of families. Participants confirmed that public transport is not accessible, whilst pedestrian spaces are usually



too narrow for wheelchair users or blocked with illegally parked cars. The time spent in B&H and Bulgaria confirmed this, and is something that is identified in several other studies too (Disability Monitor Initiative South East Europe, 2006; Panayotova, 2009). Bulgarian participants commented how for example the authorities in Sofia city claimed they made the metro service accessible, but the outcome did not do much for disabled citizens as the changes were not well thought through or implemented. For example, a disabled activist told of how she tried to reach an entrance for disabled people. She had to cross the busy road and push her way through overcrowded pedestrian areas blocked by illegally parked cars to get to the place that was supposed to be accessible, but once she got there the access was out of order. Public offices and universities in B&H increasingly have adjusted entrances and ramps. However, accessible building entrances alone cannot solve access issues, because all other routes as well as transport to those places are usually inaccessible. As in Bulgaria a majority of professionals and parents expressed the view that access is problematic and a medical doctor from Sarajevo formulated it as follows:

*We had some random actions 5-6 years ago such as building ramps and adjusting entrances; however that is now used mostly for bicycles and children's prams. Well those ramps were not made for children with disabilities in the first place, but for war veterans with physical disabilities...*

Furthermore, a majority of policy makers in B&H also mention the different treatments given to Bosnian (1992-1995) war veterans. They are people who volunteered to defend the country, saving innocent civilian lives. Unlike people who are disabled from birth or for other reasons they receive decent pensions and allowances. The attempts to equalise disability allowances across both groups' usually ends up in heated political

debates and gets dropped. It appears that in the social consciousness of B&H citizens there is an acceptance of responsibility for people who sacrificed themselves for others in war. The same support is not there for people who are disabled for other reasons. Furthermore because Bosnian Paralympics sportsmen are known for good results they also command respect and admiration. This creates a situation where disabled people are treated in stereotypical ways, either as needy victims or heroes (Shakespeare, 1997).

### 7.3.1 THE SOCIAL MODEL OF DISABILITY IN B&H AND BULGARIA

As discussed in chapter one the social model of disability is an important part of the UN Convention on the Rights of Persons with Disabilities (2006) as well as an integral part of an inclusion philosophy (Handicap International 2004; UNICEF 2005, 2007; Disability World, 2007; United Nations, 2010). However the social model has not been very influential in countries of Eastern Europe where the medical model remains the dominant discourse (UNICEF, 2010). The way participants spoke about disability reflected overwhelmingly the use of charity and medical discourse, communicating the idea that disabled people need to be helped, instead of empowered to make choices and take an active part in the society. A striking example of a lack of awareness about the social model and the internalized ideas of the medical model emerged in an interview with a young disabled woman, who is a disability activist in B&H. After asking her about the social model of disability and her views on barriers in society she responded: *'The biggest barriers are in disabled people themselves, nobody prevents them from doing anything, but they have low opinions of themselves and they are not fighting for their rights'*. It seems that the oppression results in disabled people internalising negative

views of themselves which prevents them from clearly examining their own oppression, which would be possible if they were working from the social model.

Only three participants in this study made references to the social model and barriers in society and the model's potential to contribute to the improvement of the lives of disabled people in Eastern Europe. Interestingly, all three participants who mentioned the social model of disability were employed by INGOs. One had studied in the UK and was familiar with the social model as presented in UK academia. Several other participants mentioned the social model in relation to their activities, but more as an umbrella term, for example: *'we work according to the social model'*. Once discussed further, it transpired that this includes a range of activities, from charity to social rights, with little or no empowerment and little participation by disabled people. It did not therefore correspond to the social model as developed by disability activists (see chapter one). It became clear that disability is still overwhelmingly understood as an individual phenomenon and not something that society actively creates by presenting obstacles to disabled people. This corresponds to practice discourse in B&H and Bulgaria being dominated by the medical/individual model of disability. In addition the distinction between the social model and the medical model still does not feature high among policy makers or practitioners.

What the social model of disability comprises in B&H and Bulgaria is unclear at this stage. It is certainly not the same model of disability as is found in the UK, even though it has some of the same components such as participation and rights. Under the

various influences – both political and non political - it cannot be expected that the use of the social model in B&H and Bulgaria will mirror what is found in the UK. It is likely that, under the influence of the human rights agenda B&H and Bulgaria will adopt the social model as defined internationally rather than in the UK only. For example this is how the United Nations (2010, p. 8) defines disability and the social model:

*The focus is no longer on what is wrong with the person. Instead, disability is recognized as the consequence of the interaction of the individual with an environment that does not accommodate that individual's differences and limits or impedes the individual's participation in society. This approach is referred to as the social model of disability. The Convention on the Rights of Persons with Disabilities endorses this model and takes it forward by explicitly recognizing disability as a human rights issue.*

Whilst attention is given to social barriers and participation, this definition does not say that disability is only a product of social organisation as argued by the UK social model. The basic premise is however the same; attention is shifting from the individual to society. The social organisation is seen as crucial, but much importance is also given to interaction between impairment and environment. Even though this model is largely based on the UK social model of disability, the UN emphasises diversity and importance of experiences of persons with disabilities, social rights and person first language. This model maybe influenced by a relational approach between impairment and society, as emphasised in the Nordic Relational Approach (Traustadóttir, 2004).

More recently the references to the social model are encountered sporadically in the literature and websites from B&H and Bulgaria (IBHI, 2007; Panayotova, 2009), but its

use needs further reflection. The social model is translated directly and literally as '*socijalni model*'. To me this translation does not adequately represent the philosophy of the UK social model, nor relational model, nor the UN human rights/social model. Moreover this translation presents a danger of misrepresenting the social model completely. For example '*socijalni*' in the Bosnian language is used in relation to need, to social services, or when talking about someone living in poverty. The more appropriate translation would be '*društveni model*'. This phrase would make it clear that emphasis is on '*društvo*' or society and not on social services.

Even though the social model has not been so prominent in Eastern Europe it has a place, as it is a powerful tool in uncovering and confronting oppression, and exclusion and empowering disabled children, as argued in chapter one. This is of course if the social model is understood, debated and accepted by the receiving countries.

Currently, sporadic mention of the social model does not mean that the social model is being introduced in Eastern Europe. Furthermore, being literal in translating reflects a haste and misunderstanding on the part of translator instead of something carefully considered. The social model of disability and inclusion are concepts that emerged in a fight against oppression, developed by individuals with a certain vision and understanding of the way society impacts on people with disability (Barnes & Mercer, 2001). The social model is also the basis for a political approach for activists, but as such it might not be appealing to every disabled child or adult. If these concepts are to be used in B&H and Bulgaria they need to be debated, understood and carefully considered in relation to the socio-political and economic context. This includes

translating them in the spirit of the Bosnian and Bulgarian languages, to reflect the real nature and thinking behind the social model.

Furthermore this research found that the children's rights approach, when it comes to disability, did not sink deep into the minds of policy makers, professionals or disabled people. Human rights discourse was most used by people from international organisations and human rights activists. The children themselves never mentioned it. The same applies for many parents who did not know enough about rights and entitlements: *'The problem is that parents are not informed, many parents don't know about any rights, let alone how to go about claiming those rights'* (Ana, mother, Bulgaria). At the same time the mothers were more interested in social rights than the civil and political rights of their children. The main problem is that social rights are dependent on the determination of need. Within this framework disabled people have been positioned not as holders of rights within the welfare state, but as needy and dependent people whose access to special and segregated provision is governed by a *'panoply of professional experts'* (Ellis, 2005, p. 693). Furthermore professionals often expressed views like *'these children need to be helped'* and *'we want to help them'*, instead of *'we are responsible for fulfilling their rights'*. While some of the problems are universal and arise from different interpretations of inclusion (Evans & Plumridge, 2007), the interpretation of the exclusion/inclusion agenda has some special characteristics in B&H and Bulgaria as will be discussed next.

This study identified that inclusion, children's rights, child participation, independent living and community care are western policy agendas and the UK terminology which were mostly brought into both countries by the presence of international agencies. The problems related to importing ideas and inclusion policies from abroad instead of encouraging the organic growth of inclusion initiatives in the communities, are reflected in the use of language around inclusion. For example in B&H (and something similar has been reported in Bulgaria) there are clumsy translations of some key terms. For example in B&H it became popular and appropriate, with the actions of international organisations, to use the term '*djeca sa posebnim potrebama*' which is a literal translation of the English term 'children with special needs'. Practitioners however have reported confusion when using this term, unsure if this applies to disabled children or children with special educational needs. Furthermore, inclusion in B&H and Bulgaria has been literally translated from English and used as '*inkluzija*' with various interpretations and meanings attached to it, without exploring shared understandings of what inclusion means or how it is to be carried out.

This might be one reason why inclusion is used for a variety of activities and programs, some of which can be hardly classified as inclusion. For example one institution's staff talked about inclusion when children are moved from large residential institutions to smaller type housing, even though they still remained within the premises of the institution. Attending any form of social activities, even though it might not be part of mainstream activities, is talked about as inclusion. Instead of being taken as an approach to developing society, inclusion is often restricted by different

criteria, and is therefore not something that applies to everyone. For example those children with milder impairments are more likely to be part of inclusion projects. Attaching criteria to who can and cannot be included defies the whole purpose of inclusion and it is something that societies need to strive to overcome. This indicated that the terms are used tokenistically.

Apart from using inclusion as a promiscuous concept, this study identified another potentially problematic issue. As argued in chapter one the concept of social exclusion has been on the policy agenda in European countries for some time now (Burchardt, et al., 1999; Atkinson & Davoudi, 2000), whilst the debates on social exclusion came before the social inclusion agenda. This however was not the case in B&H and Bulgaria. For example, the concept of exclusion that is widely used in international documents (UNDP, 2007; European Commission, 2009) in relation to disability is hardly ever used in national policy and practice discourse and it has clumsy literal translation attached to it. In Bosnian language this translation does not reflect the philosophy that exclusion is about inequality and discrimination. More importantly it emerged in the study that the concept that a society excludes people is unknown or rather, unacknowledged. In B&H the idea that somebody is excluded from education, because of the way the system is structured was completely unrecognised (Becirevic, 2006). This finding is supported by the review of the literature that shows that the concept of social exclusion has not been used until recently in B&H and Bulgaria. Even now, when it is used it is mostly in international agencies' reports (UNDP, 2007; UNICEF, 2010).



The reason why B&H and Bulgaria have not had the same development of exclusion debates can be related to the communist past (see chapter two). Communism presented itself as a socio-political and economic program that was about collective goods, equality, a 'one for all- all for one' ideology, concealing economic and social inequalities. Health care, education, housing and pensions were universal and this 'ideal' officially left no scope for being excluded, disadvantaged, living in poverty or suffering discrimination. Presenting arguments like this in those times would constitute a critique of the system itself, which was strongly discouraged. This ideology responded to removing disabled people and children out of public sight. Families were not supported to care for disabled children at home and frequently the only option was institutional care. This climate denied the existence of exclusion and left no room for academic debates or an examination of exclusion. It was the same with Roma people, who were either assimilated or largely unaccounted for, as they did not conform to socially imposed norms (European Roma Right Centre, 2004).

As argued in chapter one, inclusion requires understanding about and removing exclusion barriers. Not acknowledging exclusion in the first place is in itself an obstacle to inclusion. The ideas of exclusion and inclusion came in with international agencies and it will take some time for these ideas to become embedded in national awareness. The issue of language was used to illustrate problems when it comes to importing policies and global agendas from a completely different economic and social context. As argued in chapter three, this problem is not only confined to Eastern Europe, and it relates to the way global agendas are translated into local contexts (Crossley & Watson, 2003). Understanding concepts, having the language for them and agreement that

these policies are needed, are essential steps for genuine acceptance in receiving countries. So in the pool of dilemmas and problems, what is the way forward? A number of possibilities have been identified in this study and they will be outlined in the next section.

### 7.3.3 WAYS FORWARD

Considering all the evidence it appears that resources, as well as the global inclusion and human rights agenda that come with international agents, are not sufficiently utilised in B&H and Bulgaria. Foreign players exert power over domestic policymakers, a power which is not always productive, but domestic stakeholders are apprehensive about criticising their actions. Therefore some of the actions are officially endorsed, but simply passively resisted (Deacon et al., 2007). These issues need to be addressed by all national stakeholders, who need to take a more proactive approach in cooperating with foreign stakeholders, from international NGOs to big donors, creating a window for debate. In addition, government and non government organisations need to be coordinated in their efforts towards inclusion; so that they can influence donor agendas and avoid programmes and projects that are not fulfilling inclusion principles. The coordination could be improved if policies are developed systematically and evaluated regularly, with users' participation, something that is currently not the case (Maglajlic & Hodzic, 2005). Competing and sometimes contradictory inclusion strategies can be overcome if inclusion is debated as a national policy agenda, addressing all opportunities and constraints in the current context.

Furthermore public stereotypes and the way disabled people are portrayed in the media and discriminated against in public needs to be exposed and challenged. The language around disability and inclusion is very much scrutinised in disability literature in the UK (Barnes, 1992; Oliver & Barnes, 1998) but the same scrutiny was not encountered in B&H and Bulgaria. Moreover language needs to be given additional attention because of policy transfers and translations that are currently taking place, which are tied to particular language and discourses. This chapter showed how concepts can be lost in translation, reinforcing the idea that culturally appropriate terminology and understandings of concepts need to be developed. In addition the presence of children's rights organisations and their involvement in policy making is an opportunity for strengthening a children's rights approach to inclusion. This is an opportunity to move the policy agenda and the way policies are developed from a 'protective' understanding of childhood to one in which children are given participatory rights.

When a project fails to achieve sustainability or when initiatives do not take off in a non-western country, international NGOs tend to blame cultural influences for this (Burr, 2004), a problem recognised in this study too. International organisations need to change their approach in B&H and Bulgaria and start taking existing practise more seriously, instead of what Burr (2004, p. 156) describes as *'presenting themselves as rescuers and sole defenders of children's rights'*. According to Deacon et al. (2007, p. 238) *'the specific ways in which IOs relate to local players matter. They mould local knowledge and expertise, strengthening some think tanks and scholars and not others. They co-opt scholars into IOs, dissolving potential criticisms...'*. For example excluding national professionals, if

they do not speak English and do not conform to a particular agenda, from working in IOs and INGOs is a negative practice because it deepens the gap between international and national agendas and creates the existence of two opposing groups. It also lessens the opportunity for appropriate cultural translation. It would be beneficial to overcome this practice and combine the first hand experience of B&H and Bulgarian social workers, teacher, medical doctors with new developments and international best practices available through international organisations.

This chapter has considered a number of factors and players that contribute in creating changes in policies, practices and the overall situation with the disability agenda in B&H and Bulgaria. Undoubtedly there is no lack of agencies, organisations and diverse influences that work on promoting inclusion. The international human rights agenda is slowly creating a better atmosphere, as is EU accession, as well as the actions of international agencies and national NGOs. However, the strong presence of diverse actors in the disability field and policy making has both positive and negative effects, which are hardly debated. This period of changes and diverse influences could perhaps be an opportunity for debate, but also an opportunity to avoid the slowness of developments in the West and to use experiences from the West to advance inclusion. The concepts of the social model of disability and social exclusion do have the potential to contribute to this debate in B&H and Bulgaria, as long as they are not lost in translation. Further opportunities and obstacles in advancing inclusion in B&H and Bulgaria are debated in the next chapter.

## CHAPTER 8

### OBSTACLES, OPPORTUNITIES AND RECOMMENDATIONS FOR INCLUSION IN B&H AND BULGARIA

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This final chapter considers how the thesis has fulfilled the proposed research aim and outcomes. The chapter discusses the application and appropriateness, in B&H and Bulgaria, of the concepts of children's rights, social exclusion, the social model of disability and the 'new sociology of childhood' in researching exclusion and advancing the inclusion of disabled children and their families. Taking into consideration the socio-political context in B&H and Bulgaria, this concluding chapter also summarises the obstacles and opportunities for greater social inclusion and suggests ways forward by providing a set of recommendations. The final sections of the chapter address contribution to knowledge and the applicability of the thesis in advancing the inclusion of disabled children and their parents in B&H and Bulgaria. The work concludes by examining whether the current situation and recent developments in the arenas of policy and practice which affect the lives of disabled children and their families in B&H and Bulgaria constitute inclusion or merely the illusion of inclusion.

## 8.1 REVIEW OF THE RESEARCH AIM, OUTCOMES AND CONCEPTUAL APPROACH

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The aim of this study was to conduct a broad investigation concerning the general approach of the state, policy makers and professionals towards the care and support of children with disabilities and their families in B&H and Bulgaria. This aim was specifically addressed in chapters four to seven, where different aspects of exclusion and inclusion, based on the views of children, parents, professionals and policy makers were dealt with. This diversity of informants meant that problems could be identified at the policy level and disconnections between policy and practice examined. Such disconnections include for example, lack of support for families, negative views of disabled children in both societies, lack of children's participation, and ad hoc policy making. Throughout the thesis suggestions have been proposed for how these problems may be tackled, and these are drawn together in this final chapter.

Five research outcomes were initially anticipated. Firstly the study aimed to provide a rich qualitative account of the situation for families with disabled children in Bosnia & Herzegovina and Bulgaria. This was achieved by employing a methodology which gave children and parents plenty of space to both express themselves and communicate anything they saw as relevant. The flexibility of qualitative methodology and the use of semi-structured interviews, focus groups and informal observations, enabled a holistic view, one which contextualised exclusion and inclusion. It emerged that the parents and children not only use a different language to professionals when

talking about their lives, but also prioritize different issues. The adaptability of the methodology employed allowed me to spend prolonged periods of time with families, as well as with staff and children in residential institutions in the environments in which they live.

Secondly, a critique of the current policies and practices as they relate to disability in B&H and Bulgaria is developed throughout the thesis, notably in chapters six and seven. The failure to increase financial support, persistent use of traditional disability testing, reinforcement of segregated settings and lack of early childhood education are some of the national policy choices responsible for exclusion. In addition chapter seven highlights negative aspects of the international influence in B&H and Bulgaria, questioning whether the actions of the IMF and the WB are more about promoting a neo-liberal agenda and creating economic domination and dependence in the region than rectifying any shortcomings – perceived or actual - in social inclusion. In this context the thesis argues that power relations between national and international stakeholders are unbalanced and unproductive, negatively influencing policy making and inclusion efforts and need to be addressed urgently.

Thirdly the thesis findings suggest that accession to the EU is a major driver of change, which to date has been implemented through funding instruments and a range of direct and indirect pressures on acceding countries. The influence of the EU was especially evident in Bulgaria, less so in B&H. Details of how the EU influences the development of inclusion, as well as problems with accessing EU funds and translating

the inclusion agenda are discussed in chapters two and seven. Fourthly and fifthly the thesis has identified obstacles to inclusion, and the best practices for developing the inclusion and integration of children with disabilities that can be applied in other countries. These two outcomes are summarised together with recommendations for policy and practice in section 8.2 of this chapter.

#### 8.1.1 CONNECTING CONCEPTS AND THEORIES TO ADVANCE INCLUSION

Throughout this research I have reflected on the question posed by Levitas (2003, p.4) – does the idea of inclusion have the potential to be a transformative idea? I argue, here, that it does, though not in isolation. Other concepts and theoretical approaches are needed to understand exclusion and advance the inclusion of disabled children and their families in B&H and Bulgaria. This thesis began by taking the concept of social exclusion as central, but not as the sole basis for interpreting data and understanding social process. It is argued that exclusion and inclusion are not necessarily polar opposites. Rather they form a complex set of overlapping and intersecting possibilities whereby some criteria for inclusion may be met whilst others are not. Hence both concepts are more fluid than they at first appear (see chapter one).

In line with the theoretical and conceptual underpinnings presented in chapter one, the research undertaken has enabled me to test and apply the social model of disability, ‘the new sociology of childhood’ and the utility of children’s rights in examining exclusion and inclusion in B&H and Bulgaria. I have argued that constructions of disability and childhood (see chapter two) have changed little since communist times



and present an obstacle to a social inclusion agenda. These constructions are present among staff in institutions, among policy makers, a variety of professional groups and the general public. That disabled children are persistently viewed outside 'normal' childhood criteria affects the implementation of the currently popular policy agenda of social inclusion. As O'Dell (2003, p. 24) argues, universal concepts of childhood and child development oppress children who do not fit in with the supposed universality. Disabled children are not embraced within the dominant construction of childhood and consequently are positioned as problematic. This is especially the case for children with intellectual disabilities who are seen as immature, vulnerable, irrational, and unable to reach the status of adulthood. Staff and policy makers see them as unable to communicate their wishes or express choices. These children are viewed as non-contributing members of society, in need of protection, control and dependent on other people's will (Oswin, 1971; Morris, 1998; Taylor & Bogdan, 1998). This construction is associated with lower standards of service quality and reduced wellbeing for disabled children and is in complete opposition to a philosophy of inclusion that is concerned with empowerment, meaningful participation, achieving equality, being valued and removing barriers.

Furthermore the findings from B&H and Bulgaria echo a problem identified by Middleton (1999), which is that services, in spite of being designed to help, can create passivity, whilst society gives disabled children the message that they are not important. From the data emerged a view of uncertainty and lack of conviction that disabled children can be fully included, consulted, and participate in mainstream society. In addition conceptual and theoretical connectedness is evident in the

relationship between children's rights and the social construction of childhood, both highly relevant concepts for inclusion. There is evidence throughout this thesis that disabled children's rights are frequently violated and they are often constructed as powerless objects of protection rather than active agents in their own lives (Priestley, 2003). Disabled children also come in contact with a number of professionals and rehabilitators who in various ways try to fix their bodies and eradicate impairments (Priestley, 2004). This approach does little for fostering independence or building a positive identity in relation to disability (Middleton, 1999; Priestley, 2004).

Utilising the social model of disability, whilst at the same time encouraging parents and children to discuss experiences, revealed how political and personal issues are intertwined, an approach favoured by feminist researchers in disability studies (Thomas, 2001). Furthermore, applying the social model of disability to whole families (Dowling & Dolan, 2001) shows that it is the family and not just the disabled child that suffer from the effects of disabling barriers. This approach is useful when examining the situation of children living with their families, but is not so appropriate for those in permanent state care, living away from families, or for children in foster care.

Moreover as Barnes and Mercer (2003, in Barnes 2006, p.18) argue the majority of disabled children live with non-disabled parents, some of whom might not be knowledgeable about disability issues. They argue that the absorption of disability and child related benefits into the family budget, in combination with parental over protection, unemployment and prejudice, can create prolonged dependence in disabled young people and therefore act as obstacles to empowerment, independence and inclusion.

On the whole it emerged that the social model of disability and thinking related to it has not been significantly utilised in B&H and Bulgaria. Even among disability activists there appears to be no clear conceptual understanding as to how to take inclusion forward. They talk about human rights and inclusion, but their actions have been focused almost exclusively on entitlements and benefits. Whilst social rights and basic security are prerequisites for advancing other rights (Barnes and Mercer, 2001), the current approach by disability activists leaves unchallenged issues of social barriers, power issues with professionals and violation of political and citizens' rights. Sociological critiques by disabled people themselves, which were so instrumental in the UK (Oliver, 1996; Oliver & Barnes, 1998; Shakespeare, 2006) are largely missing in B&H and Bulgaria. Moreover this study has argued that the successful incorporation of the social model cannot be considered without also questioning how it may be most appropriately translated in the native languages of B&H and Bulgaria (see chapter seven), thereby contributing to debates on the application of the social model in other cultures (Stone, 1999).

Using the concept of social exclusion in relation to disabled children and their families provided new insights. For example in B&H and Bulgaria debates on social exclusion have until recently been absent. Inclusion itself appeared on the policy agenda well before exclusion was even addressed, a process quite different to other European countries. In France for example social exclusion first appeared on the political agenda in the 1970s (Popay et al., 2006) and in the UK in the 1990s (Burchardt et al., 1999). The absence of exclusion from debates in B&H and Bulgaria and the reasons for this are discussed in chapter seven. However it can be seen from applying the concept that the

situation of disabled children and their families in B&H and Bulgaria illustrates many of the aspects of social exclusion articulated by Daly (2005), Levitas (2003), Burchardt et al. (1999).

The majority of families demonstrated that the exclusion they experience is complex and multilayered, and usually composed of unfavourable economic, social and political circumstances. In addition parents described being segregated from the wider, non disabled, community confirming Saracheno's (2001) arguments about exclusion. Furthermore it emerged that parents and children suffer from what Ward (2009) terms material and discursive exclusion, material exclusion being reflected in the denial of access to education, employment, health and social care services and discursive exclusion in the use of language and in professional practices which focus on limitations and charity, whereby reasons are enunciated why disabled children cannot be consulted and need to be controlled by professionals. This is a way to justify and maintain social exclusion and as such it is ideological in its nature.

An important element that perpetuates exclusion is an overall disregard for the material poverty of the families of children with disability. This is actively encouraged by the IMF and WB in their advocacy of reductions in social benefits (see chapter 7). Worryingly, it is emerging that in B&H and Bulgaria, inclusion strategies replicate what exclusion strategies have been criticized for, diverting attention from poverty (Levitas, 2005). This approach, even if unintentional, is highly problematic as popular community strategies, such as day centres will not ipso facto be able to solve family

poverty. Hence poverty is something that needs to be addressed. Still, in both countries a general orientation towards inclusion was apparent, albeit with some differences in implementation strategies.

### 8.1.3 COMPARING INCLUSION ADVANCES IN B&H AND BULGARIA

The major differences identified between B&H and Bulgaria in relation to the social exclusion/inclusion of disabled children are firmly grounded in the socio-political past. As discussed in chapter two, totalitarian Soviet style communism has had a major influence on the Bulgarian disability agenda, something that the country is struggling to overcome. The regime rendered disabled people almost completely invisible and through an extensive network of residential care in remote places denied social differences and problems. Even though accession to the EU has stimulated and accelerated change (chapters two and seven), Bulgaria is slow in overcoming this legacy of severe exclusion of disabled children. The burden of this history explains why there is much more resistance amongst the Bulgarian public towards inclusion when compared with B&H.

In both countries the inclusion agenda has brought issues of disability into the limelight and has resulted in an increase in the development of policies and plans addressing disability. However, in Bulgaria, because of the high numbers of children in residential care, deinstitutionalisation is a policy priority, which is not the case in B&H where there are only a small number of disabled children in residential care (chapters two and five). Bulgaria continues to struggle with the deinstitutionalisation and closure

of social homes and residential special schools (UNICEF, 2007b). One reason for keeping institutions and segregated facilities open pertains to the vested interests involved in preserving employment there. Also in Bulgaria family substitute services are underdeveloped, whilst progress in this area has been noted in B&H with foster care programmes. Bulgaria is however developing community care services at a faster rate, stimulated by the EU accession pressures and funding. Even though past practices in B&H do not conform to what we would recognise as inclusion, extensive institutionalisation was never the problem that it was in Bulgaria, and so decarceration is a much less pressing issue in B&H. Furthermore this research identified that the overall attitude towards disabled children in B&H is more accepting, with less resistance to inclusion from residential places and special schools.

Recent EU pre-accession and accession processes have brought change that reflects positively on Bulgaria, which now has one of the most comprehensive lists of community based services in the region (UNICEF, 2007b) with the EU's Open Method of Coordination adding to the pressure on Bulgaria to demonstrate further positive changes. To date, B&H remains more progressive in addressing the poverty of families. It has shown greater resistance towards implementing IMF requests, although recently this resistance has been diminished somewhat by the government promise of significant cuts in the public sector in exchange for a 1.6 billion dollars Stand-By Arrangement with the IMF (International Monetary Fund, 2009). In response to the implementation of these austerity measures disabled war veterans organised protests in Sarajevo in April 2010, which turned into violent clashes with police. Because of its relatively strong central government in comparison with the highly decentralised B&H

government Bulgaria is in a better position to implement unified policies and monitor changes. In both countries the number and work of NGOs has flourished in a similar way, but they are not always fully supportive of inclusion, even though they tend to present themselves as advocates of inclusion. Moreover conceptual misinterpretations about inclusion, as well as the domination of the medical model are still present in both countries (see chapter seven).

## 8.2 OBSTACLES, OPPORTUNITIES AND RECOMMENDATIONS FOR CHANGE

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This section summarises the obstacles to and opportunities for inclusion in B&H and Bulgaria. These are briefly introduced in the table below, followed by discussion organised around national and international policies; the shift from institution to community services and professional practices. Whilst the grounds for proposing particular recommendations have been argued throughout the thesis, the overview of recommendations in this section contains particular strategies, practices and changes aimed at facilitating inclusion, which hopefully can aid B&H and Bulgaria to develop a more inclusive/integrated society for children with disabilities and their families.

Table 8. 2 Obstacles and opportunities for inclusion

Obstacles	Opportunities
<ul style="list-style-type: none"><li>- Negative societal attitudes</li><li>- Unchanged paradigms and unchallenged construction of disability</li><li>- Reliance on residential institutions and special schools and their resistance to change, especially in Bulgaria</li><li>- New developments and deinstitutionalisation strategies are frequently reproducing old practices</li><li>- Misinterpretations of exclusion and inclusion</li><li>- Contradictions between the EU and the World Bank and IMF</li><li>- Uncoordinated actions of NGOs</li><li>- Insufficient support for families</li><li>- Economic underdevelopment and strong drives towards a neo-liberal agenda</li><li>- Shortage of social workers and lack of people trained to work in inclusion</li></ul>	<ul style="list-style-type: none"><li>- EU accession, pressures, funding</li><li>- Status of the inclusion agenda, which has been developing for some time internationally</li><li>- Increasing focus on UNCRC and UNCRPD</li><li>- Presence of diverse stakeholders</li><li>- Increasing parents' advocacy and activism</li><li>- Emergence and significant growth of civil society sector</li><li>- Development of community centres and inclusive education</li><li>- Policy reforms</li><li>- Promotion of democratic governance</li><li>- Increased recognition that access and transport need to be further improved</li><li>- Some recognition that defectology needs reforming</li></ul>

This study has proposed that one of the major obstacles that must be addressed in order to achieve greater inclusion of disabled children and their families is the thinking attached to disability in B&H and Bulgaria. The understanding of disability in these countries remains focused on children's impairments and the activities that disabled children cannot do, with impairments seen as reasons for exclusion. The majority of informants in this study regarded public attitudes as a real problem in improving the situation of disabled children and their families. It would be easy to put the blame on



an uneducated public, but it must be remembered that disability was for a long time hidden in Eastern Europe. Reforming social policies and implementing inclusion projects needs to include the simultaneous education of the public. If issues of disability are publically deconstructed it will help in breaking the prejudices and misconceptions about disabled children and inclusion.

The social model of disability has successfully challenged stereotypical views in the UK and the US for over 30 years and can be used as a strategy to challenge and remove social, environmental and attitudinal barriers (Oliver, 1996; Barnes & Mercer, 2004). Furthermore disabled children would benefit from positive identification with disabled adults, who according to Middleton (1999) have a central role in challenging the view of disabled people as passive and non-contributing. Disabled boys and girls can address their issues with those who have experience of being disabled, and for all these reasons, disabled adults have a legitimate right and responsibility to be involved in issues related to disabled children.

#### 8.2.1 POLICY CHANGE AND INTERNATIONAL TRENDS

The impetus in favour of policy reforms in B&H and Bulgaria provides an opportunity to design policies and plans geared towards social inclusion. This research however has identified several problems which stand in the way. For instance the importance of developing policies supportive of whole families is not yet fully recognised and families of disabled children do not receive adequate financial support. This is

particularly true in Bulgaria. In defence of this approach Bulgarian policy makers claim that their orientation is toward supporting families with community services. This however neglects the problem that community services are far from universally available and there are in addition examples of the government's ad hoc approaches to reducing the number of children in institutions and implementing inclusive education. The research is consistent with Sotiropoulou and Sotiropoulos's (2007, p. 145) argument that the government's urgent drive to reduce the number of children in institutions, without planning alternative measures, stems largely from European Union pressures to meet the obligatory requirements, rather than from any real conviction that change is necessary.

This study indentified a range of significant problems related to policy making in B&H and Bulgaria: the lack of participation of service users, confusion when translating international policy agendas into national policies and laws and an almost complete absence of policy evaluation. Furthermore, policy makers acting within existing government structures are often poorly equipped or disinclined to negotiate the pressures and demands directed from powerful international agents (EU, IMF, WB) even when these may adversely affect citizens' welfare. As a result of this unproductive process, policy initiatives are sometimes passively resisted (Deacon et al. 2007), whilst reforms are conducted without careful planning and consideration of socio-political and economic factors. This situation results in a waste of available resources that might otherwise be directed towards developing social policies and building a welfare system that could effectively respond to the needs of citizens.

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In addition many parents, professionals and activists have felt let down either by changes or the lack of changes brought about by the accession processes. However the evidence from this research suggests that policy and practice reforms are taking place. The relative absence of research in this field and a lack of understanding of the processes involved have also caused frustration among stakeholders. As Guillen and Palier (2004) argue, changes in social policy in candidate countries are not only dependent on EU pressures, but the interaction between the EU, international organisations and the capabilities and constraints presented by domestic structures. The findings from this research are consistent with Deacon and Stubbs's (2007) assertion that post-communist social policy in Eastern Europe is being influenced by a number of international agencies with the most influential of these being the World Bank, European Union, Council of Europe and OECD.

The present work confirms Lendvai's (2004) arguments that in spite of EU failure to address core social policy competencies in Eastern European countries, the accession process has opened up new agendas for policy making with respect to disability, Roma issues, and women's issues. This is identified as a clear opportunity for change. Moreover, apart from the immediate EU policy influence, some of the IOs, as well as national and INGOs have made a real impact in formulating policy developments. This is especially the case with organisations applying a human rights approach. Even though it is not always accepted and implemented approaches based on human rights exert significant pressure on domestic actors. However there are counterarguments that other powerful actors, such as the World Bank, counteract the influence of European social policy (Deacon, 2000).

Chapter seven discussed the changes in welfare state organisation in Eastern Europe that reflect the influence of a neo-liberal agenda promoted by both the IMF and World Bank. However as Wagener (2002, p. 172) argued, the state, as legislator, regulator and organiser, remains responsible for the quality and legitimacy of welfare state transformation. However good governance and lack of available resources are serious problems standing in the way of transformation in B&H and Bulgaria. In order to improve the process of policy development and implementation more research based policy making by domestic actors is needed. Furthermore this research has identified the same issue as Sotiropoulou & Sotiropoulos (2007), that acts and legislation are not followed by guidelines and plans and budgets for realising successful implementation, and which are necessary to avoid policies failing in practice. Both countries need more professional assistance, rather than simply pressure from the EU, as many government organisations just do not have the knowledge and capacity to implement projects to EU standards. Policy making can be further improved if the processes of policy translation and transfer are addressed, instead of attempting to copy policies from other Western European countries whilst disregarding local economic, social and cultural factors.

There is a need to improve the level of cooperation between international agents and domestic stakeholders when translating international agendas into action. In this area the study identified a number of questions that require attention and further research. What is it that domestic stakeholders need when translating an international agenda into national legislations, plans and strategies? What national capacities need to be developed further? What are the communication strategies that can make this process more efficient? What are the tensions and dilemmas operating between a human rights

oriented agenda, market efficiency, social justice and opposing ideologies currently operating in an already complicated policy space? There is a need for understanding the way international pressures associated with financing and existing political agendas operate in any one country and the way in which these power dynamics are reflected in the policies of a country already heavily dependent on international support. Power dynamics between national policy makers and international policy makers need to be addressed for more balanced relations to be achieved.

#### **Box 8.1 Summary of recommendations for policy makers**

Government and NGOs stakeholders need to develop and implement policies with a policy cycle in mind (i.e. identification of needs/problems, development of policy proposals, policy implementation, and regular evaluation of policy effects) which builds upon the active participation of users.

Government, national and INGOs need to coordinate their efforts towards inclusion, and be able to influence donor agendas to ensure that all programmes and projects that are developed and implemented put inclusion principles into practice.

Once the legislation is passed, governments need to develop guidelines and programmes of implementation and designate a budget for them.

This thesis has devoted significant attention to issues of residential care (see chapters two and five). The problem is that in spite of political commitment to deinstitutionalisation only a small number of children are actually being decarcerated in Bulgaria, whilst in both countries the availability of community services for disabled children and their families is uneven (Panayotova, 2009; European Commission, 2009). There has also been little evaluation into how effective the new services actually are in meeting the needs of children and families in both B&H and Bulgaria (Maglajlic-Holicek & Residagic, 2007; Panayotova, 2009). We do know that rural exclusion is not being addressed effectively and that the understanding of the notion of community is itself ambiguous. The term may carry multiple meanings – for example referring to the nature of social relations in a geographical area or to a sense of belonging there (Cowen, 1999). Definitions are especially problematic when using community and care together, where questions about the caring capacities of the communities and the government's role in supporting this arise (Hill, 2007). As Mansell et al. (2004) suggest transition from institutional provision to services in the community should be based on the widest possible consultation with users and families, with preferably a national mandate and local agreements between all potential service provider sectors. This research in B&H and Bulgaria is consistent with Mansell et al's. (2004. p. 9) arguments contained in the EU report on deinstitutionalisation:

*service-providing agencies on their own are likely to be constrained by their past and present ways of thinking and working; the new models of service require a partnership between disabled people (and those who help and represent them) and agencies planning and providing services.*

Even though institutionalisation is a major problem in Bulgaria, until recently there was no common strategy for closing institutions (UNICEF, 2007b). The study identifies a major tension between the efforts of some stakeholders to improve existing institutions and others who believe that these institutions should be closed down completely. However, based on the model of de-institutionalisation they have been developing in Bulgaria for several years, UNICEF recently agreed with the Bulgarian government on a master strategy for de-institutionalisation (United Nations, 2009). Also the dramatic portrayal by the BBC of the Mogilno institution in Bulgaria (see chapter five) provoked public outrage and policy reactions by drawing attention to the severe injustices to disabled children unfolding in Bulgaria. Recently Kate Blewett, the director of the film returned to Bulgaria and witnessed the extraordinary impact it had had. The previously neglected and beaten children, shown in 2008, were now living in community housing, playing, and attending schools and displaying significantly raised levels of cognitive functioning (BBC, 2009). Similar change was found in this study (see chapter five).

## Box 8.2 Summary of recommendations for advancing community services

Disability assessments process and efficacy needs to be revised. New standards and procedures are necessary which involve consultation with professionals, day centres, parents and carers and disabled children (see chapter 6). This is something that international policy actors can influence.

There is a need to reorganize the current financial system which continues to create powerful incentives to maintain the existence of institutions and the number of children in them (see chapter 5).

Consideration needs to be given to strengthening the capacities of, and financial support to, parent organisations and local NGOs in delivering services in order that they can address barriers in their locality more effectively. Successful local grassroots initiatives need to be identified and supported by the government and international donors (see chapters 6 and 7).

Foster care, independent living, personal assistance and respite care need to be developed further to cover the whole country. Further research is needed to determine best practices that are culturally appropriate for B&H and Bulgaria. Evaluations will clarify what further developments are needed.

In B&H attention needs to be given to the sustainability of day centres (see chapters 4 and 6).



Box 8.2. continued

Cooperation and trust between individual NGOs should be improved, for example by having NGOs identify specialist areas and focus on these areas; by increasing their financial transparency and by demonstrating how communities are benefiting from their actions. The projects developed by NGOs in principle should not be owned by the NGOs, but by the community in which they are developed (see chapters 6 and 7).

Mechanisms for parents and carers to claim their rights and benefits should be strengthened. Advocacy campaigns by the government on the rights and entitlements should form an essential part of government action (see chapter 4).

Services need to be delivered that address the requirements of the whole family and efforts need to be made to include fathers and siblings whenever possible (see chapter 4).

Davis (2005) argues that the principles of the Convention on the Rights of the Child strongly influenced policy frameworks in Central and Eastern Europe and contributed in transforming the system of care in the region from one which is residential to one which is community-based. The research undertaken here in B&H and Bulgaria suggests that this is an overly optimistic view. However the raising of awareness about rights, as well as the potential to legally enforce the application of certain rights enshrined in the UNCRC and the UNCRPD, creates an opportunity to advance inclusion. It is expected that the situation for families with disabled children

will be given more attention once the UNCRPD (2006) begins to exert its influence. However, the protection of human rights and access to entitlements for disabled children involves an understanding of the complexity of individual and family experiences of impairment and disability in the social (including socio-economic) context (Clarke, 2006). It remains to be seen whether all the pressures that come from the EU, UNICEF, and INGOs have the sensitivity and capacity to address the social and family complexities of disabled children and their parents or carers and increase their social inclusion.

### 8.2.3 UNCHANGING PRACTICES

Inclusion needs to be implemented and supported with adequate professional practices and services. However as shown in chapters two, five and six there is evidence that current professional practices often act as an obstacle to inclusion. The focus in the literature (UNICEF 2005, 2007) is on the practice of defectology as an obstacle to inclusion. Moreover INGOs are not addressing defectology (see chapters two and six) and in implementing inclusion projects tend to leave defectologists behind. However this research gives indications that defectology when adequately reformed, can be turned into a vehicle for inclusion. This thesis suggests that segregation and segregated special education are not simple products of defectology, but arise by a complex interplay between policies, practices, culture and history. In addition this study identified that no group of professionals, and not just defectologists, have made a paradigmatic shift in implementing inclusion practices. The orientation towards individual and tragic discourse, identified among

professionals, presents an obstacle to inclusion. For instance it seems too often forgotten that inclusion requires more than placing a child in a mainstream school and developing an individual educational plan. Inclusion is about everyone in the school and the community as well as developing an inclusive service culture (Booth et al., 2000). An inclusion agenda and change in policy can give opportunities to professionals to re-examine their practice and the theories on which they base their work. At the same time, the recognition of children's rights promoted by NGOs is an opportunity that has not been sufficiently utilized.

Obstacles to inclusion have been identified in curricula for university training of professionals. To take inclusion forward systematically, major changes have to be made in the training of defectologists, special educators, social workers and other professionals. The curriculum for defectology (University of Tuzla, 2007) in B&H is overwhelmingly medically orientated, which conflicts with an inclusion philosophy that defectologists engage with when practicing in community services. In addition, in 2009 whilst presenting findings from this research to social work students in Sarajevo, it was apparent that they do not engage with issues of exclusion or children's rights and do not reflect critically on current practices. As Morris et al. (2009b, p. 234) argue, the approach of these social workers, which is based on a preoccupation with individual outcomes, is likely to limit their capacity to challenge the barriers to inclusion. However the opportunity to move practice towards inclusion was evident as students were eager to learn new methods, theories and strategies.

It was also of some concern to hear that students who are in the final stages of their social work training had never discussed child participation and never learned how to communicate with disabled children or children who use limited or no speech. Developing professional cultures that will involve communication with disabled children has to be taken seriously in both B&H and Bulgaria and recognised as a necessary ongoing process. Social workers have an important role in enabling communication with disabled children and thus contributing to the reduction of exclusion, but they need to be equipped to do so from the time of their initial training (Mitchell et al., 2009). Opportunities should be provided for students to learn from learning disabled people and those who communicate non-verbally, about their experiences and what they need from services (Mitchell et al., 2009. p.320). This advice should be taken up in B&H and Bulgaria in reforming social work education.

Collaboration emerged as a significant issue in discussions with the majority of professionals and parents who mentioned lack of communication, knowledge exchange and partnership between different ministers, agencies and services. These informants believed that a multi-disciplinary approach is required in addressing the needs and rights of children and families, but is unfortunately largely absent. When partnership does happen it has the potential to stimulate inclusion. However the customary practice is for parents or carers of disabled children to bring documentation from one service to another when attending categorisation commissions or claiming benefits. International and national NGOs, sometimes work with government agencies in delivering services or drafting policy strategies, and lessons learned from these partnerships also go undocumented and are not shared. Overall strategies for

partnerships between government services are nonexistent and underexplored in B&H and Bulgaria. Professionals and parents claimed this has a negative impact on inclusion. In particular professionals in special schools felt excluded from the inclusion agenda. This is, to an extent, the reason why special schools in Bulgaria are resistant to inclusion and see it as a threat to their practice.

Balloch and Taylor (2001) address the benefits of partnership, as well as the tension and power issues associated with it, something that needs to be explored further in B&H, as one aspect of improving services. However, they argue that partnership is a very large and broad topic with many possible research strands and it is beyond the scope of this thesis to suggest exactly how partnerships need to develop in B&H and Bulgaria. In addition, as Balloch (2007) reminds us, partnerships and collaboration can produce better results, but only if combined with other strategic steps from government.

### Box 8.3 Summary of recommendations for practice

Professionals in special schools and residential institutions need to be supported to take part in inclusion initiatives. Pedagogical institutes, ministries and international and national NGOs who work on inclusion need to include professionals from special schools in their training and seminars. In this way they are more likely to take part in developing inclusive practices, instead of being sidelined in new developments, evidence of which was encountered in the research.

Supporting defectologists to modify their training and practice to fit better with developing community social inclusion initiatives is a key recommendation from this research.

The current university training of social workers, pedagogues and teachers needs to be examined in depth. The reforms need to include training in working and communicating with disabled children, children's participation.

The above recommendations for practitioners point to the need to explore professional practices in depth, including the evaluation of pre-service and in-service training to establish how compatible they are with inclusion. Social workers need to learn about child participation, disability and exclusion. The hearts and minds of government professionals need to be won over to an inclusion agenda, but to make this possible

they need to have a shared understanding of inclusion and the potential it has for disabled children and the wider society. If they see inclusion as driven by an ideologically and politically motivated external agenda there is little chance for success. The idea of inclusion is popular but is usually pursued by professionals in international organisations who rarely have a permanent role in its development. Furthermore based on their research in Bulgaria, Sotiropoulou & Sotiropoulos (2007) argue that persistent problems exist in the undemocratic nature of public administration where feedback from practitioners is not only not valued; but worse is actively criticised and can lead to dismissal. They see this as indicative of an anti democratic state mentality in which rules are set by elites.

#### 8.2.4 IDENTIFICATION OF SUCCESSFUL PRACTICES

One of the desired outcomes of this study was to identify successful practices for developing inclusion and the integration of children with disabilities that can be used in other Eastern European countries. This section draws together successful practices identified in the course of the research. For instance, well planned and targeted international exchange was mentioned as an effective and practical way to learn about and understand best practices in other countries. Whilst for some people going to more developed countries could be demoralizing as they became aware of how better resourced others are, for others it challenged their assumptions about disability and gave them ideas for their own practice. This type of exchange is something that NGOs can organise and support.

Successful practices were encountered in local NGOs and in services provided by parents' associations, as discussed in chapter six. Taking into consideration the needs of local communities and the available resources they managed to develop innovative employment opportunities, rehabilitation and workshops for children with particular impairments, such as autism. An especially practical, and potentially life changing example was encountered in an NGO in B&H which provided transport for children in a residential special school, so that the children can return home every day instead of sleeping in the school. This initiative was hugely welcomed by both parents and children and is something that can be achieved in other residential special schools.

Successful practice encompassing service partnership in the community was identified in the work of a day centre for children with multiple disabilities '*Koraci Nade*' (*Steps of Hope*). The centre was opened in 1994 with support from *Oxfam* and has developed into an important community resource for children and parents. For several years the centre was financed by various international organisations and NGOs, though half of the financing now comes from the Ministry for Social Policy with the rest coming from various fundraising activities. This centre emphasises social models and inclusion, with activities aimed at the promotion of children's rights, rehabilitation and socialisation, and the encouragement of disabled children into mainstream schools. It also provides education for parents in order to equip them for the role of co-therapist. The centre works closely with the Faculty of Defectology in Tuzla which organises some of their practical teaching and provides student volunteers for the centre.



Another successful practice concerns the transformation of professional practice. In Bulgaria through the TEMPUS programme of international exchange in 1996, defectology was reformed and renamed as special education. Professional assumptions came under scrutiny and review, in a period when the establishment of the *Bulgarian Journal of Special Education* allowed the dissemination of project outcomes and professional debate (Tsokova & Becirevic, 2009). In Bulgaria the reform and renaming of professional defectology practices as special education practices was one of the first steps taken in reforming practices around disability in general. However it is questionable what impact this reform has had on practice since Bulgaria is still heavily dependent on institutions and special schools. In B&H defectology is significant for inclusion but remains officially unreformed. Changes were however noted between defectologists who work in community settings, INGOs and national NGOs and those who work in special schools, with the former being more enthusiastic about inclusion (Becirevic, 2006). There needs to be a timely engagement with the reform of defectology in B&H, and in other countries of Eastern Europe.

A successful practice related to the extension of fostering to disabled children has been encountered in B&H. The personal account of a boy who was transferred from an orphanage into foster care, presented in chapter four, is an example of the transformative power of well tailored interventions. Dedicated attempts by UNICEF to reintegrate children from Mogilino back into their families have been made in Bulgaria and it is a strategy that can be employed elsewhere. The NGO workers took the role of liaising between institutions and families. They sent letters to families, pictures of their children, informed them of progress and organised and supported parents' visits to the

institution. The strategy is slow but it has the potential to reunite families and reintegrate children back into communities. Another important change aimed at supporting parents and children is the increase in the financial allowance to parents, which happened in the Federation of B&H. As reported by informants, this has made a difference to living standards as well as family dynamics and is a policy option which needs to be seriously considered not just in the other part of B&H but also throughout the wider region.

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### 8.3 FINAL REFLECTIONS

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This final section addresses the contribution to knowledge made by the thesis and its potential applications. This section provides an indication to as whether the situation for disabled children and their families corresponds to one of inclusion or merely the illusion of inclusion. But first of all, something needs to be said regarding the limitations of the study.

The research approach, and the selection of informants, was organised around the aim of conducting a broad investigation concerning the general approaches of the state, policy makers, professionals and service users towards disability in B&H and Bulgaria. As such the research was not designed to investigate the in-depth specifics of how the exclusion of children with autism, physical disabilities, Down's syndrome, cerebral palsy or other specific impairments operates. However references to specific

impairments and exclusionary practices associated with it were made throughout the thesis (see chapters four and five). Furthermore difficulties were experienced in accessing children's views, as gatekeepers were unconvinced that children could make a contribution to this research. If the situation in Bulgaria had been different it would have been desirable to include more children through individual interviews and focus groups.

### 8.3.1 CONTRIBUTION TO KNOWLEDGE AND APPLICATIONS OF THE THESIS

There are several works that have examined disability issues regionally, or with a focus on particular issues such as educational inclusion and deinstitutionalisation (Amnesty International, 2002; UNICEF, 2003, 2005, 2007; Handicap International, 2004; Open Society Institute 2005; OECD 2009). However the topic of social exclusion/inclusion in Eastern Europe has not been subjected to any in-depth comparative cross national studies. To my knowledge this is the first study that provides comparative analyses of social exclusion/inclusion of disabled children and their families in B&H and Bulgaria, and as such constitutes a unique contribution to knowledge in this particular field. It is situated in an overall regional context, but with a clear focus on these two countries. The study takes a holistic approach considering historical legacies and socio-political currents, as well as contemporary policies, professional practices and community changes in examining the exclusion of disabled children and their parents. Furthermore the approach that utilises the views of children, parents and practitioners in formulating policy recommendation has not previously been applied in these countries.

On the level of professional practices this study makes an important contribution as it engages in analysing the discipline of defectology and the work of defectologists in relation to inclusion. Previously, defectology has been either criticised or overlooked entirely in the literature, whilst proponents of inclusion have failed to include defectologists in the inclusion agenda. This thesis however reveals that the discipline can be changed and transformed to support inclusion. Whilst giving recommendations as to how defectology can be reformed and accommodated within the inclusion agenda, I argue for an approach that will actively engage with aspects of defectology.

Furthermore this study analyses the interplay between national and international stakeholders, uncovering issues concerning the dominance of international financial institutions in ways which are counterproductive to inclusion. This is an issue that has been largely ignored in B&H and Bulgaria although recognised in the disability literature elsewhere (Holden, 2004). The study also reveals that strategies and practices which are used to advance inclusion in B&H and Bulgaria, for example deinstitutionalization and community care may sometimes actually replicate exclusion. Ways to remedy this situation are offered.

Methodologically the study has made advances, in the context of B&H and Bulgaria, by accessing the voices of children, parents and carers, providing previously missing data on how families and children respond to policy and practice interventions (Morris et al., 2009, p. 39). Additionally with limited knowledge of the role of translation in translating policy into practice the study has made a methodological contribution by

providing insights into the use of the Bosnian, Bulgarian and English languages in researching and interpreting issues around inclusion/exclusion and disability. Analysis of the ways key concepts are translated from English indicated significant levels of misunderstanding as to what the concepts represent. Furthermore, work with translators in Bulgaria demonstrated that translation can provide an opportunity for cross cultural research, while translators can be a source of support, aid triangulation and help in the interpretation of meaning. The cross-national policy research enabled comparisons of exclusion/inclusion issues in B&H and Bulgaria, again something that has not been previously done. On a conceptual level the study revealed a focus on inclusion but an absence of discussion concerning exclusion, not to mention lack of recognition of exclusionary barriers. In addition, the study identified (in chapter seven) that the social model of disability is interpreted in various ways which are frequently unrelated to the social model as presented in UK academic discourse.

This study opened up a number of topics that warrant further investigation, not only in B&H and Bulgaria, but also the rest of Eastern Europe. It emerged for example that although B&H and Bulgaria are preoccupied with developing policies, policy measures and practical work, more attention needs to be given to parents' activism utilising qualitative, in-depth or longitudinal studies in order to further understand how parents can be supported in advocacy for inclusion. The same applies to disabled children and young people where so far little research has been done to investigate the levels of their participation. This research has also identified problems related to young people's employment, transition from institutions and sexual relationships, all issues that warrant further investigation, along with evaluation of de-institutionalisation

projects, community centres and inclusion in schools with an emphasis on children's and parents' experiences. This would best assess the impact, as well as increase knowledge about the practical significance of inclusion initiatives.

This research identified hidden issues that need further attention; such as the bullying of disabled children in mainstream schools, as well as exclusion in special schools because of the language barrier between Roma and Bulgarian children. The picture we have of the inclusion of disabled children and their families would benefit further from an ongoing longitudinal investigation. This would provide insight into how different policy measures, such as financial aid or community centres, impact on families over time. In addition, Eastern European countries have made different advances in inclusion and there is a need to understand what theoretical and conceptual approaches are informing these changes. Apart from opening discussion on the theoretical concepts and models used in Eastern Europe, the work in this thesis has also contributed to understanding exclusion and inclusion in B&H and Bulgaria in a number of other ways.

The policy and practice recommendations given in this thesis (see sections 8.2.1 and 8.2.3) are relevant for other countries of Eastern Europe for several reasons. This is firstly because of similarities across the region in child protection systems, professional practices and currently similar socio-political changes. To these countries EU accession and aspiration to it is pivotal for policy change and reform. Insofar as B&H and Bulgaria experience strong WB and IMF influences, so do other countries of Eastern

Europe which creates common pressures on welfare structure. In relation to practice all Eastern European countries are dealing with reforming disability assessments, improving statistics, negotiating the role of a rising civil society, deinstitutionalisation and reforming systems to community based care. The whole region for example has historically adopted defectology as an approach to address disability, so the findings that defectology can be reformed and utilised in an inclusion agenda are of particular relevance. However to be applied the findings need to be disseminated.

The recommendations and main findings are likely to be useful to large stakeholders (government, international and local stakeholders), as a tool for developing their work. So far the study has benefited from cooperation with UNICEF, an organisation with strong policy inputs into Eastern Europe. Importantly, throughout the research, participants made numerous remarks about the dearth of disability studies in B&H and Bulgaria. The potential for practical applications of this thesis emerged during discussion with informants - for example when a mother and activist in B&H remarked:

*...we need something to support our arguments and advocacy. We are not scientists in this topic, we are parents and when we say something is good for our children they do not believe us, we don't have scientific evidence. We need research about us and our children.*

The plan then is to produce a summary of the thesis, in the form of a report and in accessible formats for distribution to disability and parents' organisations in B&H and Bulgaria. The aim of this is to support advocacy, fill the gap in the literature about disabled children and their families in B&H and Bulgaria, but above all for this research to empower individuals and communities (Lather, 2003).

In the beginning of the thesis I referred to my personal and professional experiences, however it was not until the end of my PhD that I understood how strongly these experiences impacted on me during the research. Whilst revisiting the concept of the social exclusion I started to recognise that I was socially excluded myself during the years when I was a refugee. Doing a PhD included years of reading and critical reflection which enabled me to recognise and understand the mechanisms of discrimination and exclusion and deconstruct this experience. Having the space and ability to understand this from a different perspective helped me in confronting feelings of discrimination and injustice that have been with me for a long time.

Apart from this personal journey I began to see the larger picture of international children's rights, social politics and policies. For this reason my continuing work for international agencies and NGOs will never be the same. I became aware of the ambiguities and complexities of inclusion and the need to frequently revisit conceptual underpinnings and critically reflect on the actual outcomes instead of adhering to an ideology in vogue. Furthermore, in the past my focus was on seeing through a single project but now I am able to attend to politics, power dynamics and issues associated with receiving foreign aid and negotiating with donors. Finally I developed a conviction that we, the Eastern European professionals and policy makers, need to have a stronger voice, as well as a more prominent international presence in informing and guiding developments in our countries.



### 8.3.2 ILLUSION OR INCLUSION?

After intense deliberation about exclusion and inclusion in B&H and Bulgaria I am left unable to claim firmly whether the situation in these countries is one of inclusion or the illusion of inclusion. The question is not an easy one to answer and others have pondered similar dilemmas (Barnes, 2006), though in different contexts. The changes in B&H and Bulgaria are developing for a variety of political, philosophical and pragmatic reasons. These are sometimes piecemeal rather than strategic responses of real conviction in relation to the rights of disabled children or to belief in the inclusion ideal. The situation in B&H and Bulgaria is changing and disability is currently on the agenda of social policy, whilst practical attempts to integrate disabled children via education and community centres have been noted.

This study showed the same problem highlighted by Vann and Šiška (2006, p. 429) who argue that the inheritance of segregation is difficult to overcome in a new political and economic system. They observe that 15 years after the transition from communism, the Czech Republic was '*still coming to terms with its legacy*'. However, in concluding this thesis about inclusion and disabled children and their families, there is a need to emphasise that B&H and Bulgaria have also come a long way in the last fifteen years. Having said this, I am not claiming these countries are close to achieving the standards of inclusion seen in Italy, the UK or Scandinavia, but that attempts to transform the system and culture from ideological and systematic exclusion to inclusion are evident. In conclusion the thesis returns to reflection on the popular, but often de-contextualised critique that Eastern Europe countries are lagging behind in inclusion in comparison to Western Europe.

It is clear that the development of inclusive disability policies and practices in Eastern Europe follows a different trajectory to that taken by Western European countries. Whilst the rest of Europe developed inclusion over a long period of time, the post communist countries are expected to join an already developed agenda in a much shorter time and without other necessary changes being in place. These other changes and supportive factors, which preceded and facilitated inclusion in Western Europe, were initiated in the 1960s. The changes included the rise in disability movements, anti-discrimination legislation, parents' activism and the increased significance of human rights (Barnes & Mercer, 2001; Oliver 2004).

At the same time, on the conceptual level, thinking has moved on from normalization and the medical model to the social model and from integration and assimilation to inclusion (Rieser, 2001). De-institutionalization was also happening gradually, provoked by poor conditions in institutions, economic changes and the early and influential critiques of institutional culture (Goffman, 1961; Oswin, 1971). These debates were strengthened by powerful critiques of the misuse of medical power; challenging discourses and practices in psychology and psychiatry; questioning the arbitrariness of psychiatric diagnosis and oppressive mental health systems (for example: Foucault, 1973; Szasz, 1983; Laing, 1985). These show that changes towards inclusion grew simultaneously from communities and activists, supported and theoretically developed by academic debates which were followed by policy and practice development.

The appearance of inclusion on the policy and practice agenda in B&H and Bulgaria has not followed the same timeline or the same sequence. Instead the development of inclusion is being attempted in a condensed form with a leap from segregation to inclusion in a significantly shorter space of time. It needs to be remembered that the commitment to segregating disabled children did not end with the transition from communism in 1989. As presented in chapter two, the years of transition with the war in B&H and economic upheavals in Bulgaria produced an even more unfavourable situation for disabled children and reinforced institutional care, because of increased unemployment, poverty, war and economic crisis.

In B&H and Bulgaria significant questioning of the appropriateness of the care of disabled children only started in the mid to late 1990s. This was encouraged by humanitarian organisations and international NGOs, so instead of being a grassroots movement it came more from the outside than the inside of the countries and communities. When integration appeared on the agenda, B&H and Bulgaria had not developed disability movements or parents' activism. These also developed later than in other countries, again with the encouragement of international organisations. This corresponds to the view of Birzea (in Oancea, 2005, p. 8) who argues that cultural transition in Eastern Europe is slower than legal, economic and political transition.

Furthermore in Eastern Europe transition has meant the erosion of previous socialist values and the promotion of capitalist ones (Pringle, 1998), again developments that have mixed consequences for disabled children. Reflecting on the past whilst

considering the present, it can be said that communism was an ideology of equality of disadvantage (Deacon, 1992), but capitalism, or the so-called free market economy, so eagerly awaited by many Eastern Europeans, did not necessarily bring prosperity or inclusion. Instead it continues to widen the gap between people and increase inequalities. The problems in reconciling capitalist ideology with inclusion of disabled people have been addressed elsewhere (Oliver, 1994b; Barnes, 2006). As argued in chapter seven, the tensions in this respect in B&H and Bulgaria are felt through the World Bank and IMF requests to reduce welfare expenditure. My argument is that these policy requirements will only deepen the exclusion of disabled children and their families, though it must be said B&H and Bulgaria have little power to resist these demands.

In relation to institutionalisation transformations are happening and disabled children are more likely to stay with their families instead of being sent to residential care. In addition disabled children may benefit from using community resources like day centres. In spite of these changes a deeper examination opens up the question as to whether inclusion is happening or whether new opportunities are creating the illusion of inclusion. This question is not addressed adequately in B&H and Bulgaria and changes aimed at inclusion are not examined, evaluated or critically reflected upon. For example, the inclusiveness of new community developments is not questioned, even though some reproduce segregation, albeit in a different form (European Commission, 2009). The problem is that even though disabled children stay in a community they are grouped in facilities like day centres or rehabilitation centres attended by disabled children only. In implementing de-institutionalisation whilst

advancing inclusion, policy makers, activists and practitioners in B&H and Bulgaria need to be aware of the issue, eloquently formulated by Bates and Davis (2004, p. 198):

*Bringing people back home demands more than relocating their beds — relationships have to change as well. In both social capital and inclusion thinking, service users are recognized as citizens, and the traditional focus on the relationship between worker and service user is replaced by an emphasis upon the reciprocal relationship between citizen and community.*

Right now, in both countries, human rights conventions are contributing to fulfilling the rights of children and, as already argued, the United Nation Convention on the Rights of Persons with Disabilities has the potential to change the situation further. However, as suggested by Panayotova (2009) clear indicators are necessary in establishing the effectiveness of the UNCRPD. Furthermore Panayotova (2009) argues for a clearer focus on the actual situation and needs of disabled children and their families, as laws and policies on the European level are focused on adults and employment. Moreover as Sotiropoulou and Sotiropoulos (2007, p. 152) argue: *'promotion of children's rights has to be understood as a necessity for society's development and not as a priority that will facilitate the country's accession to the EU'.*

In addition, in combating the exclusion of disabled children and their families, it is important to address both the causes (social barriers and lack of opportunities) and the consequences (poverty and isolation) faced by families. The experience of parents and children is that of slow change, particularly in the context of serious financial hardship resulting from loss of earning power and the expense of care. Oliver and Barnes (2006, p.1) argue that *'the rights based approach to disability would be counter-productive if pursued*

*as an end in itself rather than as a means to an end'*. This argument is relevant to the current disability agenda in B&H and Bulgaria, which heavily relies on human rights that are, unfortunately, too frequently not observed.

For that reason this thesis argues that the human rights approach is not sufficient by itself to carry inclusion forward, nor is the development of community care or welfare rights. This has already been argued by those who see welfare as a way to conceal deep seated oppressions (Oliver & Barnes, 1998). Inclusion, or rather inclusiveness needs to govern services, public spaces, schools and upbringings and it needs to be connected to the development of democracy. As such there is a need to place debates on exclusion, inclusion and development of new policies in the public domain, instead of keeping it exclusively in the circles of policy makers and civil society elites.

Still, having worked in Eastern Europe and having lived in B&H most of my life, my personal conviction is that things have moved on and improvements are visible. This research captured some of these improvements and an array of promising actions by some of the dedicated state professionals, parents, carers and NGO workers. However, my belief is that those who work on inclusion need to always aim higher, using reflection and constructive criticism to move things forward. This unfortunately has been lacking in B&H and Bulgaria. However, it needs to be stressed that the countries of Eastern Europe have been going through major economic, political and social changes in the past twenty years. They cannot therefore be expected to have developed inclusion in any manner which conforms to the ideal. Based on this research I can only

say that processes towards inclusion have been started, albeit sometimes clumsily, and it can be predicted they will develop further. Inclusion, as an idea and practice is growing in these societies and hopefully this thesis will contribute to moving it forward. It is a reason for optimism that citizens are gaining power, raising their voices and taking action, something that was unimaginable twenty years ago.

In Eastern Europe the question of inclusion is not only about ending residential care or developing community centres, but the larger issue of how disabled people are viewed and why, as Vann and Šiška (2006) discuss in relation to the status of people with learning disability in the Czech Republic. These arguments apply to disabled people everywhere and for that reason I examined issues outside of a purely economic framework, even though Oliver's argument, that exclusion from economic participation is the key to understanding social exclusion is valuable (Oliver, 1994). Considering the situation in B&H and Bulgaria, my argument is that improving the material situation of families, getting children out of institutions, making the environment accessible, and building day centres is just part of the picture. It is more a prerequisite for inclusion, whilst the real challenge is challenging those who do the excluding (Morris et al., 2009). It is about changing the minds of non-disabled people, service providers, and ensuring that non disabled children grow up respecting and valuing their disabled peers. It is about society treating exclusion as an immoral and unethical choice (Gallagher, 2001, p. 651). After years of oppression, exclusion and injustice, disabled children and their families experience achieving change like this as a long process, but one that has begun in Bosnia & Herzegovina and Bulgaria.

## References

- Abadjieva, R., 2005. *Preventing the Risks of Exclusion of Families with Difficulties: Comment Paper, Bulgaria*. Peer Review in the Field of Social Inclusion Policies: Italy 2005. European Commission.
- Ainscow, M. & Haile-Giorgis, M., 1998. *The Education of Children with Special Needs: Barriers and Opportunities in Central and Eastern Europe*. Innocenti Occasional Papers, Economic and Social Policy Series, no. 67. Florence: UNICEF International Child Development Centre.
- Ajdinski, LJ. & Florian, L., 1997. Special education in Macedonia. *European Journal of Special Needs Education*, 12 (2), pp. 112-126.
- Alderson, P., 2002. Young children's health care rights and consent. In: B. Franklin, ed. 2002. *The New Handbook of Children's Rights: Comparative Policy and Practice*. New York: Rutledge.
- Allan, J., 2006. The repetition of exclusion. *International Journal of Inclusive Education*. 10 (2-3), pp. 121-133.
- Alcock, P., Erskine, A. & May, M. eds., 1998. *The Student's Companion to Social Policy*. Oxford: Blackwell Publishers Ltd.
- Alston, P. Tobin, J. & Darrow, M. 2005. *Laying the foundations for children's rights: An independent study of some key legal and institutional aspects of the impact of the convention on the rights of the child*. Florence: UNICEF Innocenti Research Centre.
- Amnesty International, 2002. *Bulgaria: Far from the eyes of society. Systematic discrimination against people with mental disabilities*. London: Amnesty International.
- Archard, D., 2004. *Children: Rights and childhood*. 2<sup>nd</sup> ed. Oxon: Routledge.
- Archard, D., 2006. Children's Rights. *Stanford Encyclopaedia of Philosophy*. Available at: <http://plato.stanford.edu/entries/rights-children/> [Accessed 25 May 2009]
- ARK, 2008. *The problem: Bulgaria's institutionalised children- key facts: Briefing note: institutions in BG*. Available at: [http://0101.netclime.net/1\\_5/2e5/248/122/BG%20insts%20overview%20ARK%20Jan%2008.pdf](http://0101.netclime.net/1_5/2e5/248/122/BG%20insts%20overview%20ARK%20Jan%2008.pdf) [Accessed 22 June 2009]
- Arksey, H. & Knight, P., 1999. *Interviewing for Social Scientists*. London: SAGE Publication Ltd.



Armstrong, F., 2003. *Spaced out: policy, difference and the challenge of inclusive Education*. London: Kluwer Academic Publishing.

Aries, P., 1962. *Centuries of Childhood: a social history of family life*. London: Cape.

Atkinson, R. & Davoudi, S., 2000. The Concept of Social Exclusion in the European Union: Context, Development and Possibilities. *Journal of Common Market Studies*, 38 (3), pp. 427-448.

Atkinson, A.B., Cantillon, B., Marlier, E. & Nolan, B. 2005. *Taking forward the EU social inclusion process*. Luxembourg, Council of the European Union (European Union, 11-05-0180-E). Available at: <http://eprints2.eprints.soton.ac.uk/42868/n#> [Accessed 5 March 2010]

Balloch, S., 2007. Researching partnerships: politics, ethics and pragmatism. *Research, Policy and Planning* 25(2/3), pp. 71-78.

Balloch, S. & Taylor, M. eds., 2001. *Partnership Working: Policy and Practice*. Bristol: The Policy Press.

Banach, M., Iudice, J., Conway, L., Leslie J. & Couse, L.J., 2010. Family Support and Empowerment: Post Autism Diagnosis Support Group for Parents. *Social Work With Groups*, 33 (1), pp. 69 – 83.

Barnes, C., 1992. *Disabling Imagery and the Media: An Exploration of the Principles for Media Representations of Disabled People*. The British Council of the Organisations of disabled people. Ryburn Publishing. Available at: <http://www.leeds.ac.uk/disability-studies/archiveuk/Barnes/disabling%20imagery.pdf> [Accessed at: 22 September 2009]

Barnes, C., 1997. A Legacy of Oppression: A History of Disability in Western Culture. In: L. Barton & M. Oliver, eds. 1997. *Disability Studies: Past Present and Future*. Leeds: Disability Press. Ch. 1.

Barnes, C., 2001. 'Emancipatory' Disability Research: project or process? Public Lecture at City Chambers, Glasgow, 24, October 2001. Available at: <http://www.leeds.ac.uk/disability-studies/archiveuk/Barnes/glasgow%20lecture.pdf> [Accessed 21 June 2009]

Barnes, C., 2004. Disability, disability studies and the academy. In: J. Swain, S. French, C. Barnes & C. Thomas, eds. 2004. *Disabling Barriers-Enabling Environments*. 2<sup>nd</sup> ed. London: Sage Publication Ltd. Ch. 4.

Barnes, C., 2006. Independent Futures: policies practices and the illusion of inclusion Background notes to a verbal presentation. *European Network for Independent Living*. Friday November 3rd 2006. Available at: <http://www.leeds.ac.uk/disability-studies/archiveuk/Barnes/valencia%20presentation%20Colin.pdf> [Accessed 20 May 2010]

Barnes, C. & Mercer, G., 2001. The politics of disability and the struggle for change. In: L. Barton, ed. 2001. *Disability, Politics and the Struggle for Change*. London: David Fulton Publishers.

Barnes, M. & Morris, K., 2007. Networks, Connectedness and Resilience: Learning From the Children's Fund in Context. *Social Policy and Society*. 6 (2), pp. 193-197.

Barnes, M. & Morris, K., 2008. Strategies for the Prevention of Social Exclusion: An Analysis of the Children's Fund. *Journal of Social Policy*, 37( 2), pp. 251-270

Bates, P. & Davis, F. A., 2004. Social capital, social inclusion and services for people with learning disabilities. *Disability & Society*, 19 (3), pp. 195- 207

BBC, 2009. *New lives for Bulgaria's abandoned children*. Available at: <http://news.bbc.co.uk/1/hi/world/europe/8307256.stm>  
[Accessed 23 February 2010]

Bebbington, J. & Collison, D., 2006. NGOs, civil society and accountability: making the people accountable to capital. *Accounting, Auditing & Accountability Journal*, 19 (3), pp. 319-348.

Becirevic, M. 2006. Meanings of Inclusive Education in Bosnia and Herzegovina. Unpublished MPhil thesis. Cambridge University.

Becirevic, M., 2007. *Inclusion of Roma Children in B&H Education: Principal Challenges and Solutions*. Sarajevo: Open Society Fund in Bosnia and Herzegovina.

Béland, D., 2007. The social exclusion discourse: ideas and policy change. *Policy and Politics*. 35 (1) pp. 123-139.

Beresford, B., Sloper, P., Baldwin, S. & Newman, T., 2003. What Works For Children? Meeting the needs of families with disabled children: What Works & What's promising? *Evidence Network publication*. Available at: <http://www.whatworksforchildren.org.uk/docs/Briefings/Disability%20Briefing.pdf>  
[Accessed 13 March 2010]

Bernal, C., 2006. Challenging the 'tragedy'. In: H. Warner, ed. 2006. *Meeting the Needs of Children with Disabilities: Families and professional facing the challenges together*. London and New York: Routledge. Ch.3.

Blum R., Stanton G.H., Sagi S. & Richter E. D., 2008. "Ethnic cleansing" bleaches the atrocities of genocide. *European Journal of Public Health*, 18 (2), pp. 204-209.

Blewett, K., 2007. Documentary film. *Bulgaria's Abandoned Children*. BBC 4, Tuesday 11 December 2007. midnight-1.30am.

- Bühler-Niederberger, D., 2010. Introduction: Childhood Sociology: Defining the State of the Art and Ensuring Reflection. *Current Sociology*, 58 (2), pp. 155-164.
- Booth, T. & Ainscow, M. eds., 1998. From Them to Us: An international study of inclusion in education. London: Routledge.
- Booth, T. and Booth, W., 1996. Sound of Silence: narrative research with inarticulate subjects. *Disability & Society*, 11 (1), pp. 55-69.
- Booth, T., Ainscow, M., Black-Hawkins, K., Vaughan, M. & Shaw, L., 2000. *Index for Inclusion: developing learning and participation in schools*. Bristol: Centre for Studies on Inclusive Education.
- Bosnjak, V. & Stubbs, P., 2006. *Towards a New Welfare Mix for the Most Vulnerable: Reforming Social Services in Bosnia-Herzegovina, Croatia and Serbia*. Available at: <http://www.eizg.hr/AdminLite/FCKeditor/UserFiles/File/EIZ%202006%20Conference%20Proceedings-Bosnjak-Stubbs.pdf> [Accessed 20 March 2009]
- Braithwaite, J., Carroll, R., Mont, D. & Peffley, K., 2008. Disability & Development in the World Bank FY2000–2007. SP Discussion paper. No.0808.
- BRIA, 2002. Bill of Rights in Action, Emerging Democracies in Easter Europe and Russia: How Are They Doing? Constitutional Rights Foundation, Winter 2002 (19:1). Available at: <http://www.crf-usa.org/bill-of-rights-in-action/bria-19-1-b.html>. [Accessed 5 January 2010]
- Broster, K. & Warner, H., 2006. Getting it right-the initial diagnosis. In H. Warner, ed. 2006. *Meeting the Needs of Children with Disabilities: Families and professional facing the challenges together*. London and New York: Routledge. Ch. 5.
- Bryman, A., 2004. *Social Research Methods*. 2<sup>nd</sup> ed. Oxford: Oxford University Press
- Bulgarian Helsinki Committee, 2002. *General Overview of the Bulgarian System of Special School; Monitoring by Bulgarian Helsinki Committee*. Available at: [http://www.bghelsinki.org/upload/resources/2002\\_SpecialSchools\\_intro.doc](http://www.bghelsinki.org/upload/resources/2002_SpecialSchools_intro.doc). [Accessed 15 May 2008]
- Bulgarian Helsinki Committee, 2008. *Outstanding Problems on the Implementation of Bulgaria's Obligations under UN Convention on the Rights of the Child*. Sofia: Bulgarian Helsinki Committee.
- Burchardt, T., Le Grand, J. & Piachaud, D., 1999. Social Exclusion in Britain 1991-1995. *Social Policy and Administration*, 33 (3), pp. 227-244.
- Burchardt, T. & Huerta, C., 2008. Introduction: Resilience and Social Exclusion. *Social Policy and Society*. 8 (1), pp. 59–61.

Burke, M., 1994. *Child Institutionalisation and Child Protection in Central and Eastern Europe*; UNICEF. International Child Development Centre. Florence: Innocenti Occasional Papers.

Burr, R., 2002. Global and local approaches to children's rights in Vietnam. *Childhood*. 9 (1), pp. 49-61.

Burr, R., 2004. Children's rights: international policy and lived practice. In: M.J. Kehily, ed. 2004. *An Introduction to Childhood Studies*. Buckingham: Open University Press. Ch.

Bury, M., 1996. Defining and researching disability: challenges and responses. In: C. Barnes & G. Mercer, eds. 1996. *Exploring the Divide: Illness and Disability*. Leeds: The Disability Press. Ch.2.

Byrne, B., 2006. Qualitative interviewing. In C. Seale, ed. 2006. *Researching Society and Culture*. 2<sup>nd</sup> edition, London: SAGE Publications. Ch.14

Cameron, C., 2009. Tragic but brave or just crips with chips? Songs and their lyrics in the Disability Arts Movement in Britain. *Popular Music*. 28 (3), pp. 381-396

Campbell, L., 2002. Rights and Disabled Children: In B. Franklin, ed. 2002. *The New Handbook of Children's Rights: Comparative Policy and Practice*. New York: Rutledge,

Carpenter, S. & Carpenter, B., 2002. Working with Families. In B. Carpenter, ed. 2002. *Families in Context-Emerging trends in Family Support and Early Intervention*. London: David Fulton Publishers. Ch. 2.

Carter, R., 2005. *Family Matters: A Study of Institutional Childcare in Central and Eastern Europe and the Former Soviet Union*. London: EveryChild.

Castle, S., 2008. Citing graft, EU cancels 220 million subsidy to Bulgaria. *The New York Times*, October 25. Available at:

<http://www.iht.com/articles/2008/11/25/europe/union.php>

[Accessed 12 November 2009]

Cavet, J. & Sloper, P., 2004. Participation of Disabled Children in Individual Decisions About their lives and in Public Decisions about service Development. *Children & Society*, 18 (4), pp. 278-290.

Cehovic, A. & Zahirovic, S., 2006. 'Jedna Strana Medalje'- Izvjestaj istrazivanja: Pregled najboljih praksi u oblasti invalidnosti u Bosni i Hercegovini. Sarajevo: IBHI

Celinska, D., 2004. Personal Narratives of Students With and Without Learning Disabilities. *Learning Disabilities Research and Practice*. 19 (2), pp. 89-98.

Central Intelligence Agency, 2009. *The World Factbook*. Available at:  
<https://www.cia.gov/library/publications/the-world-factbook/index.html>  
[Accessed 23 November 2009]

Cerami, A., 2006. *Social Policy in Central and Eastern Europe: The Emergence of the New European Welfare Regime*. New Brunswick and London: Transaction Publishers.

Chappell, L. A., 1997. From Normalisation a to Where? In: L. Barton & M. Oliver, eds. 1997. *Disability Studies: Past Present and Future*. Leeds: The Disability Press. Ch.3.

Clarke, H. 2006. *Preventing Social Exclusion of Disabled Children and Their Families*. Research Report. No 782. The University of Birmingham. Available at:  
<http://www.wwda.org.au/hclarke1.pdf> [Accessed 9 May 2009]

Clavering E., 2007. Enabling carers to care: Processes of exclusion and support for parents of young disabled children. *Benefits: The Journal of Poverty and Social Justice*. 15(1), pp. 33-44.

Clavering, E., Goodley, D. & McLaughlin, J., 2006. *ESRC Parents, Professionals and Disabled Babies: Identifying Enabling Care: Executive summary: Developed version for dissemination*. Available at <http://www.shef.ac.uk/disabledbabies/>  
[Accessed 11 April 2010]

Coates, A., Farnsworth, K. & Zulauf, M., 2001. *Social Exclusion and Inclusion: Partnership for neighbourhood London*. South Bank University.

Cocks, A., 2009. Respite Care for Disabled Children: micro and macro reflections. *Disability & Society*. 15 (3), pp. 507-519.

Cohen, L., Manion, L. & Morrison, K., 2000. *Research Methods in Education*. 5<sup>th</sup> ed. London: RoutledgeFalmer

Connors, C. & Stalker, K., 2003. *The views and Experiences of Disabled Children and Their Siblings: A Positive Outlook*. London: Jessica Kingsley Publishers Ltd.

Connors, C. & Stalker, K., 2007. Children's experiences of disability: pointers to social model of childhood disability. *Disability & Society*, 22 (1), pp. 19-33.

Corbin-Dwyer, S. & Buckle, J.L . 2009. The Space Between: On Being an Insider-Outsider in Qualitative Research. *International Journal of Qualitative Methods*, 8 (1), pp. 54-63.

Council of Europe, 2010. *Report by Thomas Hammarberg Commissioner for Human Rights of the Council of Europe*. Strasbourg: Council of Europe.

Cowen, H., 1999. *Community Care, Ideology and Social Policy*. Hemel Hempstead: Prentice Hall Europe.

Cross, M., 1998. *Proud Child, Safer Child: A Handbook for Parents and Carers of Disabled Children*. London: The Woman's Press Ltd.

Crossley, M. & Watson, K., 2003. *Comparative and International Research in Education: Globalisation, Context and Difference*. London: RoutledgeFalmer

Cuk, M., 2007. *Analiza postojećih sistema i institucionalnih modela i preporuke za reforme*. POI B&H (2007) Studija politike u oblasti invalidnosti. Sarajevo: Nezavisni biro za humanitarna pitanja (IBHI).

Daly, M., 2006. *Social Exclusion as Concept and Policy Template in the European Union*, Cambridge, Ma.: Working Paper no 135, Minda de Gunzburg Center for European Studies: Harvard University.

Daniels, H. ed., 2005. *An Introduction to Vygotsky*. 2<sup>nd</sup> ed. London: Routledge.

Davidson, B., 2000. The interpreter as institutional gatekeeper: The social-linguistic role of interpreters in Spanish-English medical discourse. *Journal of Sociolinguistics*, 4(3), pp. 379-405

Davis, R., 2005. *Promising Practices in Community-based Social Services in CEE/CIS/Baltic: Framework for Analysis*. USAID, Washington

Davis, J. & Hill, M., 2006. Introduction. In: K. Tisdall, J. Davis, M. Hill & A. Prout, eds. 2006. *Children, young people and social inclusion*. Bristol: The Policy Press. Ch.1.

Davis, J. & Hogan, J., 2004. Research with Children: ethnography, participation, disability, self-empowerment. In: C. Barnes and G. Mercer, eds. 2004. *Implementing the Social Model of Disability: Theory and Research*. Leeds: The Disability Press. Ch.11.

Davis, J. & Watson, N., 2000. Disabled children's right in everyday life: problematising notions of competency and promoting self-empowerment. *The International Journal of Children's Rights*, Vol 8, pp. 211-228.

Deacon, B., 1992. East European Welfare: Past, Present and Future in Comparative Context. In B. Deacon, ed. 1992. *The New Eastern Europe-Social Policy Past, Present and Future*. London: Sage Publication Ltd. Ch.1.

Deacon, B., 2000. Eastern European welfare states: the impact of the politics of globalisation. *Journal of European Social Policy*, 10 (2), pp. 146-161.

Deacon, B., Hulse, M. & Stubbs, P., 1997. *Global Social Policy: international organizations and the future of welfare*. London: Sage.

Deacon, B., Lendvai, N. & Stubbs, P. 2007. Conclusions. In: B. Deacon & P. Stubbs, eds., 2007. *Social Policy and International Interventions in South East Europe*. Cheltenham: Edward Elgar Publishing Limited. Ch. 12.

Deacon, B. & Stubbs, P. eds., 2007. *Social Policy and International Interventions in South East Europe*. Cheltenham: Edward Elgar.

Deacon, B. & Vidinova, A., 1992. Social Policy in Bulgaria. In: B. Deacon, ed.1992. *The New Eastern Europe. Social Policy Past, Present and Future*. London: Sage Publication Ltd. Ch. 3.

Delamont, S., 2004. Ethnography and Participant Observations. In: C. Seale, G. Gobo, J.F., Gubrium & D. Silverman, eds. 2007. *Qualitative Research Practice*. London: SAGE Publications Ltd. Ch.13

de Laine, M., 2000. *Fieldwork, Participation and Practice: Ethics and Dilemmas in Qualitative Research*. London: Sage Publications, Ltd.

Denzin, N., 1998. The Art and Politics of Interpretation. In N. Denzin & Y. Lincoln, eds. 1998. *Collecting and Interpreting Qualitative Materials*. London: SAGE Publications. Ch.12

Denzin, N. & Lincoln, Y. 1998. Introduction: Entering the Field of Qualitative Research. In N. Denzin & Y. Lincoln, eds. 1998. *Collecting and Interpreting Qualitative Materials*. London: SAGE Publications. Ch.1.

Des Power, B.B. & Blatch, P., 2004. Education in a Recovering Nations: Renewing Special Education in Kosovo. *Exceptional Children*. 17 (4), pp. 485-495.

DFID UK, 2005. *Zaposljavanje, pružanje socijalnih usluga i nevladin sektor*. Ured za međunarodni razvoj vlade Ujedinjenog Kraljevstva. DiFD UK.

Disability Monitor Initiative South East Europe, 2006. *Free Movement of People with Disabilities in South East Europe: An Inaccessible Right?* Belgrade: Handicap International Regional Office for South East Europe.

Disability World, 2007. *Mental Disability Advocacy Centre Clarifies Advances of UN Convention for those with Mental Disabilities*. Issue No 28, January, 2007. Available at: [http://www.disabilityworld.org/01\\_07/mdac.shtml](http://www.disabilityworld.org/01_07/mdac.shtml) [Accessed 5 December 2007]

Dnevni Avaz, 2009. Tuesday, December 1<sup>st</sup>, 2009. Year XV. No 5111, avaz -roto press. Sarajevo.

Dowling, M., 1999. Social Exclusion, Inequality and Social Work. *Social Policy and Administration*, 33 (3), pp. 245-261.

Dowling, M. & Dolan, L., 2001. Families with Children with Disabilities-Inequalities and the Social Model. *Disability & Society*, 16 (1), pp. 21–35.

Drever, E., 2003. *Using Semi-structured Interviews in Small Scale Research: a teachers guide*. University of Glasgow: The SCRE Centre.

ECF, 2003. Early Childhood Forum. *Inclusion Policy Statement*.

Available at:

[http://ncb.originx.net/webeditor/enterprise/packages/sys\\_ncb/ncb883mg\\_16405254115639p45u225630441/website/dotpdf/open%20access%20-%20phase%201%20only/ecf\\_inclusion\\_policy\\_statement\\_1006.pdf](http://ncb.originx.net/webeditor/enterprise/packages/sys_ncb/ncb883mg_16405254115639p45u225630441/website/dotpdf/open%20access%20-%20phase%201%20only/ecf_inclusion_policy_statement_1006.pdf)

[Accessed 4 May 2010]

Edmonds, L., 2005. Mainstreaming community based rehabilitation in primary health care in Bosnia and Herzegovina, *Disability & Society*, 20 (3), pp. 293-309.

Edwards, R., 1998. A critical examination of the use of interpreters in the qualitative research process. *Journal of Ethnic and Migration Studies*, 24 (2), pp. 197-208.

Edwards, A., 2007. Working Collaboratively to Build Resilience: A CHAT Approach. *Social Policy and Society*. 6 (2), pp. 255-264.

Ellis, K., 2005. Disability rights in practice: the relationship between human rights and social rights in contemporary social care. *Disability & Society*, 20(7), pp. 693-706

Erdei, I., 2004. 'The Happy Child' as an Icon of Socialist Transformation. In: J. Lampe & M. Mazower, eds. 2004. *Ideologies and National Identities: The Case of Twentieth-Century Southeastern Europe*. Budapest: CEU Press.

Erikson, E.H., 1950. *Childhood and Society*. New York: Norton.

Esping-Andersen, G., 1990. *The Three Worlds of Welfare Capitalism*. Cambridge: Polity Press,

Esposito, N., 2001. From Meaning to Meaning: The Influence of Translation Techniques on Non-English Focus Group Research, *Qualitative Health Research*, 11 (4), pp. 568-579.

EUROCHILD, 2010. *Children in alternative care - National Surveys, -2nd Edition*. Brussels: EUROCHILD.

European Commission, 2009. *Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care*. Directorate-General for Employment, Social Affairs and Equal Opportunities.

European Commission, 2010. Gender mainstreaming active inclusion policies. Luxemburg: Publication Office of the European Union.



- European Communities, 2010. *2010 European Year for Combating Poverty and Social Exclusion*. European Commission, Employment, Social Affairs and Equal Opportunities. Available at: <http://www.2010againstpoverty.eu/about/?langid=en> [Accessed 10 March 2010]
- European Roma Rights Centre, 2004. *The Non-Constituents- Rights Deprivation of Roma in Post-Genocide Bosnia and Herzegovina*. Country Report Series No 3. Budapest: European Roma Rights Centre.
- Etzioni, A., 2006. The Unique Methodology of Policy Research. In: M. Moran, Rein, M. & Goodin, E.R. eds. 2006. *The Oxford Handbook of Public Policy*. Oxford: Oxford University Press.
- Evans, R. & Plumridge, G., 2007. Inclusion, Social Networks and Resilience: Strategies, Practices and Outcomes for Disabled Children and their Families. *Social Policy and Society*, 6 (2), pp. 231-241.
- Federation of B&H, 2009. *Strategy for Equalising Opportunities for Persons with Disabilities in Federation of Bosnia and Herzegovina 2010-2014*. Draft. Sarajevo: Working group lead by Federal Ministry of Labour and Social Policy.
- Filep, B., 2009. Interview and translation strategies: coping with multilingual settings and data. *Social Geography Discussions*, 5 (1), pp. 29-49.
- Finch, J., 1999. Developing Policy-Oriented Qualitative Research. In: A. Bryman & R. Burgess, eds. 1999. *Qualitative Research, Volume IV*. London: Sage Publication. Ch. 76.
- Fink, S., 1996. The Anti- Genocide Movement on American College Campuses: A growing Response to the Balkan War. In: T. Cushman & S. G. Mestrovic, eds. 1996. *This Time We Knew: Western Responses to Genocide in Bosnia*. New York: New York University Press. Ch. 12.
- Finkelstein, V., 1993. Disability: a social challenge or an administrative responsibility. In: J. Swain, V. Finkelstein, S. French & M. Oliver, eds. 1993. *Disabling Barriers-Enabling Environments*. London: Sage Publication Ltd. pp. 34-44.
- Finkelstein, V., 2001. *The Social Model Of Disability Repossessed*. Manchester Coalition of Disabled People. February, 2002. Available at: <http://www.leeds.ac.uk/disability-studies/archiveuk/finkelstein/soc%20mod%20repossessed.pdf> [Accessed 25 April 2010]
- Flick, U., 2002. *An Introduction to Qualitative Research*. London: Sage Publication, Ltd.
- Florian, L. Ed. 2007. *The Sage Handbook of Special Education*. London: Sage Publications, Ltd.

- Fontana, A. & Frey, J., 2005. The Interview: from Natural Stance to Political Involvement. In: N. Denzin and Y. Lincoln, eds. 2005. *The Sage Handbook of Qualitative Research*. 3<sup>rd</sup> ed. Thousand Oaks: Sage Publication. Ch. 27
- Foucault, M., 1973. *The birth of the clinic: An Archaeology of Medical Perception*. London: Tavistock Publication Ltd.
- Franklin, B., 2002. Children's Rights: a brief progress report. In: B. Franklin, ed. 2002. *The New Handbook of Children's Rights: Comparative Policy and Practice*. New York: Routledge.
- Franklin, A. & Sloper, P., 2006. Participation of Disabled Children and Young People in Decision-Making within Social Services Departments: A survey of current and recent activities in Social Services in England. *British Journal of Social Work*, 36 (5), pp. 723-741.
- French, S., 2004. 'Can you see the rainbow?' The roots of denial. In: J. Swain, S. French, C. Barnes & C. Thomas, eds. 2004. *Disabling Barriers-Enabling Environments*. London: Sage Publication Ltd. Ch.12.
- French, S., 2010. Cut-off: how we spent our time in a residential school. *British Journal of Learning Disability*, 38 (2), pp. 112-119.
- Gallagher, D., 2001. Neutrality as a Moral Standpoint, Conceptual Confusion and the Full Inclusion Debate. *Disability & Society*, 16 (5) pp. 637-654
- Gilmore, L. & Chambers, B., 2010. Intellectual disability and sexuality: Attitudes of disability support staff and leisure industry employees. *Journal of Intellectual & Developmental Disability*, 35(1), pp. 22-28.
- Gindis, B., 1995. Disabled Child in the Sociocultural Milieu: Vygotsky Quest. *School Psychology International*, 16 (3), pp. 155-166.
- Gindins, B., 2010. *Understanding Your Child's Medical Report: OLIGOPHRENIA*. Available at: <http://www.bgcenter.com/oligophren.htm> [Accessed 2 February 2010]
- Glaser, B. & Strauss, A., 1999. *The Discovery of Grounded Theory: strategies for qualitative research*. New York: Aldine De Gruyter.
- Gligorijevic, J., 2007. *Inicijacija pred fajront, posljednji pioniri u SFRJ*. Vreme, [internet], 29 November. Available at: <http://www.vreme.com/cms/view.php?id=536673> [Accessed 4 December 2009]
- Gobo, G., 2004. Sampling, representativeness and generalizability. In: C. Seale, G. Gobo, J.F. Gubrium & D. Silverman, eds. 2007. *Qualitative Research Practice*. London: SAGE Publications Ltd. Ch. 26.

Goffman, E., 1961. *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. Harmondsworth: Pelican Books.

Goodley, D. & Tregaskis, C., 2006. Storying Disability and Impairment: Retrospective Accounts of Disabled Family Life. *Qualitative Health Research*, 16 (5), pp. 630-646.

Government of B&H, 2006. *The Law on Amendment of the Law of social care 2006*. Official Gazette, No 21.

Government of Bosnia and Herzegovina, 2009. *Strategy for Social Inclusion in Bosnia and Herzegovina*. Council of Ministers- Directorate for Economic Planning. Bosnia and Herzegovina.

Government of Bulgaria, 2006. *Policy on improvement of life quality of people with disabilities placed at specialized institutions and on development of social services within the community*. Available at: <http://www.mlsp.government.bg/en/integration/euro/chapter-13/euro/08.Disabled%20people/Disability%20policy%20-%20Amnesty.doc> [Accessed 15 March 2009]

Government of Bulgaria, 2008. *National Report on Strategies for Social Protection and Social Inclusion 2008-2010*. European Council, National Strategic Reports. Available at: [http://ec.europa.eu/employment\\_social/spsi/strategy\\_reports\\_en.htm](http://ec.europa.eu/employment_social/spsi/strategy_reports_en.htm) [Accessed 10 October 2009]

Gow, J., 2003. *The Serbian Projects and its Adversaries: a strategy of war crimes*. London: Hurst & Co.

Grant, G. & Ramcharan, P., 2001. Views and Experiences of People with Intellectual Disabilities and Their Families. (2) The Family Perspective. *Journal of Applied Research in Intellectual Disabilities*, 14 (4), pp. 364-380.

Groves, L., 2006. *Desk Review of Social Exclusion in the Western Balkans*. London: DFID.

Graungaard A. H. & Skov, L., 2006. Why do we need a diagnosis? A qualitative study of parents' experiences, coping and needs, when the newborn child is severely disabled. *Child: care, health and development*, 33 (3), pp. 296-307.

Grunewald, K., 2003. *Close the Institutions for Intellectually disabled- Everyone can live in the Open Society*. Available at: <http://www.independentliving.org/docs7/grunewald2003.html> [Accessed 16 December 2008]

Guillen, A. & Palier, B., 2004. Introduction: Does Europe Matter? Accession to the EU and Social Policy Developments in Recent and New Member States. *Journal of European Social Policy*, 14 (3), pp. 203-209.

Hammersley, M., 2002. Discourse analysis: a bibliographical guide. Available at: <http://www.tlrp.org/rcbn/capacity/Activities/Themes/In-depth/guide.pdf> [Accessed 23 January 2009]

Handicap International, 2004. *Izvan Deinstitutionalizacije-nestabilna tranzicija ka sistemu koji pruža mogućnosti u jugoistočnoj Evropi*. Belgrade: Disability Monitor Initiative South East Europe.

Hantrais, L. & Mangen, S., 1996. Method and Management of Cross-National Social Research. In L. Hantrais & S. Mangen, eds. 1996. *Cross-national Research Methods in the Social Sciences*. London: Pinter. pp. 1-13.

Hantrais, L. & Mangen, S., 1999. Preface: Cross-National Research. *International Journal of Social Research Methodology*, 2 (2), pp. 91-92.

Harding, L.F., 1991. *Perspectives in Child Care Policy*. Essex: Longman Group UK Limited.

Hart, R., 1992. *Children's Participation: From Tokenism to Citizenship*. Florence: UNICEF Innocenti Research Centre.

Harzing, A., 2005. Does the use of English- language Questionnaires in Cross-national Research Obscure National Difference? *International Journal of Cross Cultural Management*, 5 (2), pp.213-224

Heaton, J., Noyes, J., Sloper, P. & Shah, R. 2005. Families' experiences for caring for technology- dependent child: a temporal perspective. *Health and Social Care in the Community*. 13(5), pp. 441-450.

Herod, A., 1999. Reflections on interviewing foreign elites: praxis, positionality, validity, and the cult of the insider. *Geoforum*, 30 (4), pp. 313-327.

Hill, M., 2007. The role of communities in care. In: Balloch, S. & Hill, M. Eds. 2007. *Care, community and citizenship: Research and practice in a changing policy context*. Bristol: The Policy Press

Hill, M., Davis, J., Prout, A. & Tisdall, K., 2004. Moving the Participation Agenda Forward. *Children and Society*, 18 (2), pp. 77-96.

Hill, M. & Tisdall, K. 1997. *Children and Society*. Essex: Addison Wesley Longman Limited.

Hoare, M., 2007. *The History of Bosnia: From the Middle Ages to Present Day*. London: Saqi Books.

Hodge, N. & Runswick-Cole, K., 2008. Problematising parent-professional relationship in education. *Disability & Society*. 23 (6), pp. 637-647.

- Holden, C., 2004. The global economy of care. In: J. Swain., S. French., C. Barnes & C. Thomas, eds. 2004. *Disabling Barriers-Enabling Environments*. 2<sup>nd</sup> ed. London: Sage Publication Ltd. Ch. 40.
- Hopf, C., 2004. Qualitative Interviews: An Overview. In: U. Flick., E. von Kardorff & I. Steinke, eds. 2004. *A Companion to Qualitative Research*. London: SAGE Publications Ltd. Ch. 5.2.
- Hreinsdóttir, E. & Stefánsdóttir, G., 2010. Collaborative life history: different experiences of spending time in an institution in Iceland. *British Journal of Learning disability*, 38 (2), pp. 103-109.
- Huberman, M. & Miles, M., 1998. Data Management and Analysis Method. In: N. Denzin & Y. Lincoln, eds. 1998. *Collecting and Interpreting Qualitative Materials*. London: SAGE Publications. Ch. 7.
- Hughes, B., 2004. Disability and the body. In: J. Swain., S. French., C. Barnes & C. Thomas, eds. 2004. *Disabling Barriers-Enabling Environments*. 2<sup>nd</sup> ed. London: Sage Publication Ltd. Ch. 9.
- Iarskaia-Smirnova, E., 1999. What the Future will Bring I Don't Know: Mothering Children with Disabilities in Russia and the Politics of Exclusion. *Frontiers: A Journal of Women Studies*, 20 (2), pp. 68-86.
- IBHI, 2007. *Disability Policy Study in Bosnia and Herzegovina. Support to the Disability Policy Development in B&H*. Sarajevo: Independent Bureau for Humanitarian Issues.
- International Monetary Fund, 2009. *Bosnia and Herzegovina: Request for Stand-By Arrangement*. Staff Report. IMF Country Report No. 09/226. Available at: <http://imf.org/external/pubs/ft/scr/2009/cr09226.pdf> [Accessed 25 March 2010]
- James, A. & Prout, A. eds., 1997. *Constructing and Reconstructing Childhood: Contemporary Issues in the Sociological Study of Childhood*. London: Falmer Press.
- Jehoel-Gijsbers, G. & Vrooman, C., 2007. *Explaining Social Exclusion: Theoretical model tested in Netherlands*. The Hague: The Netherlands Institute for Social Research.
- Jenks, C., 1996. *Childhood (Key ideas)*. London: Routledge.
- Jobert, A., 1996. Comparing Education, Training and Employment in Germany, the United Kingdom and Italy. In L. Hantrais & S. Mangen, eds. 1996. *Cross-national Research Methods in the Social Sciences*. London: Pinter. Ch. 6.
- Jones, A., 2006. *Genocide: A Comprehensive Introduction*. London: Routledge.

- Jones, M. & Marks, L.A. B., 1997. Beyond the Convention on the Right of the Child: The right of children with disabilities in international law. *International Journal of Children's Rights*. 5 (2), pp. 177-196.
- Kaldor, M., 2005. *New & Old Wars*. Cambridge: Polity Press.
- Kamberelis, G. & Dimitriadis, G., 2005. Focus Group-Strategic Articulation of Pedagogy, Politics, and Inquiry. In: N. Denzin & Y. Lincoln, eds. 2005. *The Sage Handbook of Qualitative Research*. 3<sup>rd</sup> ed. London: Sage Publication, Inc. Ch.35.
- Kamerman, S.B., 2001. *Social Exclusion and Children-Background and Context*. Social Exclusion and Students with Special Educational Needs. In: *Conference Social Exclusion and Children*. Columbia University Institute for Child and Family Policy, 3-4 May, 2001.
- Kapborg I. & Bertero, C., 2002. Using an interpreter in qualitative interviews: does it threaten validity. *Nursing Inquiry*, 9(1), pp. 52-6.
- Kehily, M.J. ed., 2004. *An Introduction to Childhood Studies*, Buckingham: Open University Press.
- Kelle, U., 2004. Computer-Assisted Qualitative Data Analysis. In: C. Seale, G. Gobo, J.F. Gubrium & D. Silverman, eds. 2007. *Qualitative Research Practice*. London: SAGE Publications Ltd. Ch. 28.
- Kelly, B., 2005. 'Chocolate...makes you autism': impairment, disability and childhood identities. *Disability & Society*. 20 (3), pp. 261-275.
- Kelly, M. & Ali, S., 2006. Ethics and Social Research. In: C. Seale, ed. 2006. *Researching Society and Culture*. 2<sup>nd</sup> ed. London: SAGE Publications. Ch. 10.
- Kenny, K. & McGilloway, S., 2007. Caring for children with learning disabilities: an exploratory study of parental strain and coping. *British Journal of Learning Disability*, 35 (4), pp. 221-228.
- Kilkelly, U., 2002. Disability and children: the Convention on the Rights of the Child (CRC). In: G. Quinn & T. Degener, eds. 2002. *Human Rights and Disability: The current use and future potential of United Nations human rights instruments in the context of disability*. United Nations
- King, M., 2007. The Sociology of Childhood as Scientific Communication: Observations from a sociological systems perspective. *Childhood*, 14 (2), pp. 193-213.
- Kirk, S.A. & Glendinning C., 2002. Supporting 'expert' parents - professional support and families caring for a child with complex health care needs in the community. *International Journal Of Nursing Studies*, 39(6), pp. 625-635.

- Klein, N., 2007. *The Shock Doctrine: The Raise of Disaster Capitalism*. London: Penguin Books Ltd.
- Kollontai, A., 1920. Communism and the Family. *Selected Writings of Alexandra Kollontai*. Allison & Busby. Translated by Alix Holt.
- Kulagina, E.V., 2003. The Social and Economic Situation of Families with Handicapped Children. *Russian Education and Society*, 45 (11), pp. 42-61. English translation from Russian text, Sharpe Inc.
- Laing, R.D., 1985. *Wisdom, Madness and Folly: The making of a Psychiatrist*. London: Macmillan London Limited.
- Lansdown, G., 2005. *The Evolving Capacities of the Child*. Innocenti Insight. 05/18. Florence: UNICEF Innocenti Research Centre.
- Lather, P., 2003. Issues of Validity in Openly Ideological Research: Between a Rock and a Soft Place. In: Y. Lincoln & N. Denzin, eds. 2003. *Turning Points in Qualitative Research: Tying Knots in a Handkerchief*. Lanham: AltaMira Press. Ch. 9.
- Lendvai, N., 2004. The weakest link? EU accession and enlargement: dialoguing EU and post-communist social policy. *Journal of European Social Policy*, 14 (3), pp. 319-333.
- Lendvai, N., 2007. Europeanization of social policy? Prospects and challenges for South East Europe. In: B. Deacon & P. Stubbs, eds. 2007. *Social Policy and International Interventions in South East Europe*. Cheltenham: Edward Elgar Publishing Limited. Ch. 2
- Lendvai, N. & Stubbs, P., 2007. International Actors and Making of Social Policy in South Eastern Europe: Framing New Approaches. In: *Ss Cyril and Methodius, Institute of Social Work and Social Policy*. Faculty of Philosophy, Skopje University. Skopje: Friedrich Ebert Stiftung. Ch. 3.
- Lepir, Lj., 2007. Presentation of a project: Early detection of children with special needs and their developmental problems. *UNICEF, South East Europe Consultation*. Sofia, Bulgaria. Available at: [http://www.unicef.org/ceecis/protection\\_7069.html](http://www.unicef.org/ceecis/protection_7069.html) [Accessed 17 December 2009]
- Levitas, R., 2003. The Idea of Social Inclusion. Paper presented on 2003 Social Inclusion Research Conference. Available at: <http://www.ccsd.ca/events/inclusion/papers/rlevitas.htm> [Accessed 23 February 2010]
- Levitas, R., 2005. *The Inclusive Society? Social Exclusion and New Labour*. Basingstoke: Palgrave.
- Li, S. & Seale, C., 2007. Learning to Do Qualitative Data Analysis: An Observational Study of Doctoral Work. *Qualitative Health Research*, 17 (10), pp. 1442-1452.

- Liamputtong, P., 2007. *Researching the Vulnerable*. London: Sage Publication Ltd.
- Lincoln, Y., 2002. Emerging Criteria for Quality in Qualitative and Interpretive Research. In: N. Denzin & Y. Lincoln, eds. 2002. *The Qualitative Inquiry Reader*. London: Sage Publications, Inc. Ch.19.
- Lincoln, Y. & Guba, E., 2003. Ethics: The Failure of Positivist Science. In: Y. Lincoln & N. Denzin, eds. 2003. *Turning Points in Qualitative Research: Tying Knots in a Handkerchief*. Lanham: AltaMira Press. Ch.10
- Liotta, P. H. 2001. Paradigm Lost :Yugoslav Self-Management and the Economics of Disaster. *Balkanologie*. 5 (1-2). Available at: <http://balkanologie.revues.org/index667.html> [Accessed 13 February 2009]
- Maglajlic, R. A & Hodzic E., 2005. *Politicka participacija. Postoji li puna participacija gradjana u javnom zivotu?* Sarajevo: Open Society Fund.
- Maglajlic-Holicek, R.A. & Residagic, E.K ., 2007. Bosnia and Herzegovina. In: B. Deacon & P. Stubbs, eds. 2007. *Social Policy and International Interventions in South East Europe*. Cheltenham: Edward Elgar Publishing, Inc. Ch. 8.
- Malcom, N., 1996. *Bosnia a Short History*. London: Macmillan.
- Malofeev, N., 1998. Special Education in Russia: Historical Aspects. *Journal of Learning Disabilities*, 31 (2), pp. 191-185.
- Mangen, S., 1999. Qualitative research methods in Cross-national settings. *International Journal of Social Research Methodology*, 2 (2), pp.109-124.
- Mann, M., 2004. *The Dark-Side of Democracy: Explaining Ethnic Cleansing*. Cambridge: Cambridge University Press.
- Manning, N., 2004. Diversity and Change in Pre-Accession Central and Eastern Europe Since 1989. *Journal of European Social Policy*, 14 (3), pp. 211-232.
- Manning, C., 2008. *Bye-bye Charlie: stories from the vanishing world of Kew Cottages*. Sydney: University of New South Wales Press.
- Mansell, J., 2006. Deinstitutionalisation and community living: Progress, problems and priorities. *Journal of Intellectual & Developmental Disability*, 31(2), pp. 65–76.
- Mansell, J., Beadle-Brown, J. & Clegg, S., 2004. The situation of large residential institutions in Europe. In G. Freyhoff., C. Parker., M. Coué & N. Greig, eds. 2004. *Included in Society*. Brussels: Inclusion Europe. Ch. 3.



- Martens, K., 2002. Mission Impossible? Defining Nongovernmental Organizations. *International Journal of Voluntary and Nonprofit Organizations*, 13 (5), pp. 271-285.
- Mayall, B., 2000. The sociology of childhood in relation to children's rights. *The International Journal of Children's Rights*, 8 (3), pp. 243-259.
- Melzig, R., Petric, M., & Sprout, R., 2005. *Education in Eastern Europe and Eurasia, Working Paper Series on the Transition Countries*. Washington DC: USAID.
- Mestan, S., 2006. *Fundamental Lessons and Forthcoming Challenges in the Process of Reform of the Childcare System in Bulgaria*. Available at: [http://www.unicef.org/ceecis/p1\\_2\\_1.ppt#272,17,LONG TERM STATE POLICY OBJECTIVES](http://www.unicef.org/ceecis/p1_2_1.ppt#272,17,LONG TERM STATE POLICY OBJECTIVES) [Accessed 30 October 2007]
- MDRI, 2006. *Hidden Suffering: Romania's Segregation and Abuse of Infants and Children with Disabilities*. Washington: Mental Disability Rights International.
- Middleton, L., 1999. *Disabled Children: Challenging Social Exclusion*. London: Blackwell Science, Ltd.
- Migration Policy Institute, 2010. *The Roma of Eastern Europe: Still Searching for Inclusion*. Available at: <http://www.migrationinformation.org/Feature/display.cfm?ID=308> [Accessed 29 January 2010]
- Miles, M. & Huberman, M., 1994. *Qualitative Data Analysis: an Expanded Sourcebook*. 2<sup>nd</sup> ed. London: Sage Publication Inc.
- Mitchell, W., Franklin, A., Greco, V., & Bell, M., 2009. Working with Children with Learning Disabilities and/or who Communicate Non-verbally: Research Experiences and their Implications for Social Work Education, Increased Participation and Social Inclusion. *Social Work Education*, 28 (3), pp. 309 -324.
- Ministry of Labour and Social Policy of the FB&H, Ministry of Health and Social Welfare of the Republika Srpska, UNICEF and Save the Children UK, 2006. *Policy on Protection of Children without Parental Care and Families at Risk in Bosnia and Herzegovina 2006-2016*. Available at: <http://www.unicef.org/ceecis/BiH-NatPol.pdf> [Accessed 5 May 2008]
- Mirfin-Veitch, B. & Bray, A., 2002. Grandparents: part of the family. In: B. Carpenter, ed. 2002. *Families in Context-Emerging trends in Family Support and Early Intervention*. London: David Fulton Publishers. Ch. 7.

- Merkens, H. 2004. Selection Procedure, Sampling, Case Construction. In: U. Flick., E. von Kardorff & I. Steinke, eds. 2004. *A Companion to Qualitative Research*. London: SAGE Publications Ltd. Ch. 4.4.
- Monk, L., 2010. Exploiting patient labour at Kew Cottages, Australia, 1887-1950. *British Journal of Learning Disability*, 38 (2), pp. 86-94.
- Montgomery, H., 2009. *An Introduction to Childhood: An Anthropological Perspective on Children's Lives*. Chichester: Wiley-Blackwell.
- Moore, S., Melchior, L. & Davis, J., 2008. 'Me and the 5 P's': Negotiating Rights-Based Critical Disabilities Studies and Social Inclusion. *International Journal of Children's Rights*, 16 (2), pp. 249-262.
- Morris, J., 1991. *Pride Against Prejudice: Transforming Attitudes to Disability*. London: The Women's Press.
- Morris, J., 1998. Still Missing? Volume 1- The experiences of disabled children and young people living away from their families. London: The Who Cares Trust.
- Morris, J., 2001. Social exclusion and young disabled people with high levels of support needs. *Critical Social Policy*, 21(2), pp. 161 - 183.
- Morris, J., 2003. Including All Children: Finding Out about the Experiences of Children with Communication and/or Cognitive Impairments. *Children and Society*, 17 (2), pp. 337-348.
- Morris, K. & Barnes, M., 2008. Prevention and social exclusion: new understanding for policy and practice. *British Journal of Social Work*, 36 (6), pp. 1194-211.
- Morris, K., Barnes, M. & Balloch, S., 2009. Social Exclusion and Social Work: Questions for the Future. *Social Work Education*, 28 (3), pp. 230 -236.
- Morris, K., Barnes, M. & Mason, P. 2009. *Children, Families and Social Exclusion: New approaches to prevention*. Bristol: The Policy Press.
- Morrow, V., 2008. Editorial: Changing times at Childhood: finding a conceptual home? *Childhood*, 15 (3), pp. 301-307.
- Morse, J., Barrett, M., Mayan, M., Olson, K. & Spiers, J., 2002. Verification Strategies for Establishing Reliability and Validity in Qualitative Research. *International Journal of Qualitative Methods*, 1(2), pp. 1-19.
- Natek, K. & Natek, M., 2004. *Drzave Svijeta*. 3<sup>rd</sup> ed. Zagreb: Mozaik Knjiga.

Oakley, A., 2003. Interviewing Women: A Contradiction in Terms. In: Y. Lincoln & N. Denzin, eds. 2003. *Turning Points in Qualitative Research: Tying Knots in a Handkerchief*. Lanham: AltaMira Press . Ch. 11.

Oancea, A., 2005. 15 Years On: Educational Transitions in Central and Eastern Europe. Directions for Educational Research and Policy in the Post-Communist EU Accession and Candidate Countries. *Scientific Report of the ESF SCSS Exploratory Workshop*. Oxford, United Kingdom, 8-10 July 2005.

O'Dell, L., 2003. Distinctly different? Descriptions of the sexually abused and 'non abused' child. *Educational and Child Psychology*, 20 (1), pp. 22-33.

O'Dell, L., 2008. Commentary- Suffering children, dead babies and the appeal of the universal child. *Annual Review of Critical Psychology*, 6, pp. 134-138.

O'Driscoll, D. & Walmsley, J., 2010. Absconding from Hospitals: a means of resistance? *British Journal of Learning Disability*, 38 (2), pp. 97-102.

OECD, 2006. *Education policies for students at risk and those with disabilities in south eastern Europe. Bosnia-Herzegovina, Bulgaria, Croatia, Kosovo, FYR of Macedonia, Moldova, Montenegro, Romania and Serbia*. Paris: OECD- Organisation for Economic Cooperation and Development in Europe.

OECD, 2007. *Education Policies for Students at Risk and those with disabilities in South East Europe*. Findings from the follow up visits- Field visits October 2006-January 2007. EDU/EDPC (2007) 21. Paris: OECD- Organisation for Economic Cooperation and Development in Europe.

OECD, 2009. *Students with Disabilities, Learning Difficulties and Disadvantages in the Baltic States, South Eastern Europe and Malta: Educational Policies and Indicators*. Paris: OECD and European Commission

Olher, M. R., 2004. Translation & discourse, *Acta Scientiarum. Human and Social Sciences*, 26 (1), pp. 73-79.

Oliver, M., 1983. *Social Work with Disabled People*. London: Macmillan.

Oliver, M., 1994. *Politics and Language: Understanding the Disability Discourse*. University of Sheffield. Disability Archive UK. Available at: <http://www.leeds.ac.uk/disability-studies/archiveuk/Oliver/pol%20and%20lang%2094.pdf> [Accessed 5 June 2009]

Oliver, M., 1994b. *Capitalism, Disability and Ideology: A Materialist Critique of the Normalization Principle*. Disability Archive UK. Available at: <http://www.leeds.ac.uk/disability-studies/archiveuk/Oliver/cap%20dis%20ideol.pdf> [Accessed 17 May 2010]

Oliver, M., 1996. *Understanding Disability: From Theory to Practice*. Basingstoke: Macmillan.

Oliver, M., 2004. The Social Model in Action: if I had a hammer. In: C. Barnes & G. Mercer, eds. 2004. *Implementing the Social Model of Disability: Theory and Research*. Leeds: The Disability Press. Ch.2.

Oliver, M. & Barnes, C. 1998. *Disabled People and Social Policy-From Exclusion to Inclusion*. Essex: Addison Wesley Longman Limited.

Oliver, M. & Barnes, C., 2006. *Disability politics and the disability movement in Britain: Where did it all go wrong?* Available at: <http://www.leeds.ac.uk/disability-studies/archiveuk/Barnes/Coalition%20disability%20politics%20paper.pdf> [Accessed 3 February 2010]

Ombudsman, B&H, 2009. *Specijalni izvjestaj o stanju u ustanovama za zbrinjavanje mentalno invalidnih lica u BiH*. Institucija Ombudsmana/Ombudsmana za ljudska prava Bosne i Hercegovina. Available at: [http://www.ombudsmen.gov.ba/odjeli/Invalidi\\_knj.pdf](http://www.ombudsmen.gov.ba/odjeli/Invalidi_knj.pdf) [Accessed 5 January 2010]

Open Society Institute, 2005. *Rights of People with Intellectual disabilities-access to education and employment. Monitoring report for Bulgaria*. Budapest: Open Society Institute.

Open Society Institute, 2007. *EU monitoring and advocacy program, equal access to quality education for Roma*. Vol. 1, Bulgaria, Hungary, Romania, Serbia. Budapest: Open Society Institute.

Oswin, M., 1971. *The Empty Hours: A Study of the Week-end Life of Handicapped Children in Institutions*. London: Allen Lane The Penguin Press.

Panayotova, K., 2009. *Country report on the implementation of policies supporting independent living for disabled people: Country Bulgaria*. University of Leeds: Academic Network of European Disability experts (ANED).

Piaget, J., 1952. *The Origins of Intelligence in Children*. New York: International University Press.

Peake, A., 2003. Child abuse: The hidden narrative. *Educational and Child Psychology*, 20 (1), pp. 34-43.

Pesikan, A., 2003. Human rights: From knowledge to conduct. In: K. Kati, ed. 2003. *Balkan Yearbook of Human Rights 2003: Human Rights Education in the Balkans*. Balkan Human Rights Network. Tirana: Morava.

Phipps, S. & Curtis L., 2001. *The Social Exclusion of Children in North America*.

Departments of Economics and Community Health and Epidemiology. Halifax: Dalhousie University.

Preston, G., 2006. Families with disabled children, benefits and poverty. *Benefits*, 14 (1), pp. 39-43.

Priestley, M., 2003. *Disability: A Life Course Approach*. Cambridge: Polity Press

Priestley, M., 2004. Generating Debates: Why we need a life course approach to disability issues. In: J. Swain., S. French., C. Barnes & C. Thomas, eds. 2004. *Disabling Barriers-Enabling Environments*. 2<sup>nd</sup> ed. London: Sage Publication Ltd. Ch. 14.

Pringle, K., 1998. *Children and Social Welfare in Europe*. Buckingham: Open University Press.

Popay, J., Enoch., E., Johnson, H. & Rispel., L., 2006. *Social Exclusion Knowledge Network (SEKN): Scoping of SEKN and proposed approach*. The Central Co-ordinating Hub for the SEKN. Lancaster: Lancaster University.

Powell, C., 1996. Whose voice? Whose feelings? Emotions; the theory and practice of feminist methodology. In: K. Carter & S. Delamont, eds. 1996. *Qualitative Research: The Emotional Dimension*. Hants: Ashgate Publishing Limited. Ch. 1.

Prior, L., 2004. Documents. In: C. Seale., G. Gobo., J.F., & D. Silverman, eds. 2007. *Qualitative Research Practice*. London: SAGE Publications Ltd. Ch. 22

Puljiz, V., 2007. Social Policy of the Post Yugoslav Countries: Legacy, Transition problems, Perspectives. In: "Ss Cyril and Methodius", Institute of Social Work and Social Policy. Skopje University. Skopje: Friedrich Ebert Stiftung. Ch.4.

Rabiee, P., Sloper, P. & Beresford, B., 2005. Doing research with Children and Young People Who Do Not Use Speech for Communication. *Children and Society*, 19 (5), pp. 385-396.

Rees, L., 2008. *Behind Closed Doors: Stalin: The Nazis and the West*. London: BBC Books.

Research and Documentation Centre Sarajevo, 2009. Available at:  
<http://www.idc.org.ba/>  
[Accessed 27 December 2009]

Renold, E., Holland, S., Ross, N. & Hillman, A., 2008. 'Becoming participant': Problematizing 'Informed Consent' in Participatory Research with Young People in Care. *Qualitative Social Work*, 7( 4), pp. 427-447.

Residagic, K.E., 2006. Non-governmental sector at crossroads: Bosnia and Herzegovina 10 years on. In: K. E. Residagic, ed. 2006. *Children and Youth Issues in human rights issues in Bosnia and Herzegovina*. Sarajevo: International Bureau for Humanitarian Issues.

Reynaert, D., Bouverne-de-Bie, M. & Vandeveld, S., 2009. A Review of Children's Rights Literature Since the Adoption of the United Nations Convention on the Rights of the Child. *Childhood*, 16(4), pp. 518 - 534.

Republic of Bulgaria, 2010. *National Program: European Year for Combating Poverty and Social Exclusion*. Ministry of Labor and Social Policy of the Republic of Bulgaria.

Available at:

[http://www.2010againstpoverity.eu/extranet/bg\\_national\\_programme\\_en.pdf](http://www.2010againstpoverity.eu/extranet/bg_national_programme_en.pdf)  
[Accessed 10 March 2010]

Reuters, 2010. Police battle Bosnians protesting IMF-imposed cuts. Reuters Online, [Internet] 22 April.

Available at: <http://www.reuters.com/article/idUSLDE63K213>  
[Accessed 17 may 2010].

Rieser, R., 2001. The Struggle for Inclusion: The Growth of a Movement. In: L. Barton, ed. 2001. *Disability, Politics & Struggle for Change*. London: David Fulton Publishers. Ch.11.

Rioux, M., 2001. Bending towards justice. In: L. Barton, ed. 2001. *Disability, Politics & the Struggle for Change*. London: David Fulton Publishers

Rist, R.C., 1998. Influencing the Policy process With Qualitative Research. In N. Denzin & Y. Lincoln, eds. 1998. *Collecting and Interpreting Qualitative Materials*. London: SAGE Publications. Ch.14

Ryen, A., 2004. Ethical Issues. In: C. Seale., G. Gobo., J.F. Gubrium & D. Silverman, eds. 2007. *Qualitative Research Practice*. London: SAGE Publications Ltd. Ch.14.

Ryen, A., 2008. Trust in cross-cultural research. *Qualitative Social Work*, 7 (4), pp. 448-465.

Ryan, G. W. & Bernard, R., 2003. Data Management and Analysis Method. In: N. Denzin & Y. Lincoln, eds. 2003. *Collecting and Interpreting Qualitative Materials*. 2<sup>nd</sup> ed. London: Sage Publication Ltd. pp. 269-802.

Ryan, S. & Runswick-Cole, K., 2008. Repositioning mothers: mothers, disabled children and disability studies. *Disability & Society*, 23 (3), pp. 199- 210.

Ryan, S. & Runswick- Cole, K., 2009. From Advocate to Activist? Mapping the Experiences of Mothers of Children on the Autism Spectrum. *Journal of Applied Research in Intellectual Disabilities*, 22 (1), pp. 43-53.

Roberts, B. & Hamilton, C., 2010. 'Out of darkness into the light': a life-story from Ireland. *British Journal of Learning Disability*, 38 (2), pp. 127-132.

- Robinson, C. & Stalker, K., 1998. *Growing up with disability*. London: Jessica Kingsley Publishers, Ltd.
- Robson, C., 2002. *Real World Research*. 2<sup>nd</sup> ed. Oxford: Blackwell Publishing.
- Roche, J. & Tucker, S., 2003. Extending the Social Exclusion Debate: An Exploration of the Family Lives of Young Carers and Young People with MEE. *Childhood*, 10 ( 4 ), pp. 439-456.
- Roma Education Fund, 2009. *Advancing Education of Roma in Bosnia and Herzegovina: County Assessment and the Roma Education Fund Strategic Directions*. Budapest: Roma Education Fund.
- Rubin, H. J & Rubin, I.S., 1995. *Qualitative interviewing- the Art of Hearing Data*. London: Sage Publication
- Runswick-Cole, K., 2007. The Tribunal was the most stressful thing: more stressful than my son's diagnosis or behaviour': the experiences of families who go to the Special Educational Needs and Disability Tribunal (SENDisT). *Disability & Society*, 22( 3), pp. 315- 328.
- Russell, P., 2003. Access and Achievement or Social Exclusion? Are the Government's Policies Working for Disabled Children and Their Families?. *Children & Society*, 17 (3), pp. 215-225.
- Quinn, G. & T. Degener, eds., 2002. *Human Rights and Disability: The current use and future potential of United Nations human rights instruments in the context of disability*. United Nations
- Qvortrup, J., 2007. Editorial: A reminder. *Childhood*, 14 (4), pp. 395-400.
- Sabot, E. C., 1999. Dr Jekyll, Mr H(i)de: the contrasting face of elites at interview. *Geoforum*, 30(4), pp. 329-335.
- Salcin-Watts, E. and Salcin-Watts, H., 2007. *Ovo je moja kuca*. Pazaric: Zavod za zbrinjavanje djece i omladine Pazaric.
- Saraceno, C., 2001. Social Exclusion, Cultural Roots and Diversities of a Popular Concept. In: *Conference Social Exclusion and Children*. Columbia University Institute for Child and Family Policy, 3-4 May, 2001.
- Sarenac, O., Bajramovic, M. & Sunkic, Z., 1999. *Integration-one possible experiment in BiH*. Sarajevo: UNOPS
- Save the Children, 2000. *Access for All-Helping to Make Participatory Process Accessible for Everyone*. London: Save the Children.

- Save the Children, 2003. *A Last Resort: the growing concern about children in residential care. Save the Children's position on residential care*. London: International Save the children Alliance.
- Saurugger, S. & Radaelli, C.M., 2008. The Europeanization of Public Policies: Introduction. *Journal of Comparative Policy Analysis*, 10 (3), pp. 213-219.
- Saxonber, S. & Sirovatka, T., 2006. Failing Family Policy in Post-communist Central Europe. *Journal of Comparative Policy Analysis*, 8 (2), pp. 185-202.
- Seale, C., 2004. Quality in qualitative research. In: C. Seale., G. Gobo., J.F. Gubrium, & D. Silverman, eds. 2007. *Qualitative Research Practice*. London: SAGE Publications Ltd. Ch. 24
- Seale, C., 2006. Generating grounded theory. In: C. Seale, ed. 2006. *Researching Society and Culture*. 2<sup>nd</sup> ed. London: SAGE Publications. Ch.18
- Seale, C., 2006b. Coding and analysing data. In: C. Seale, ed. 2006. *Researching Society and Culture*. 2<sup>nd</sup> ed. London: SAGE Publications. Ch.23
- Sebba, J. & Ainscow, M., 1996. International developments in inclusive schooling: Mapping the issues. *Cambridge Journal of Education*, 26(1), pp. 5-18.
- Sen, A., 2000. *Social Exclusion: Concept, Application, and Scrutiny*. Social Development Papers No. 1. Office of Environment and Social Development Asian Development Bank. Available at: [http://www.adb.org/documents/books/social\\_exclusion/](http://www.adb.org/documents/books/social_exclusion/) [Accessed 17 July 2009]
- Shakespeare, T., 1997. Cultural Representation of Disabled People: dustbins for disavowal? In: L. Barton & M. Oliver, eds. 1997. *Disability Studies: Past Present and Future*. Leeds: Disability Press. Ch. 13.
- Shakespeare, T. 2006. *Disability Rights and Wrongs*. Oxon: Routledge.
- Shakespeare, T. & Watson, N. 2002. *The social model of disability: an outdated ideology?* Available at: <http://www.leeds.ac.uk/disability-studies/archiveuk/Shakespeare/social%20model%20of%20disability.pdf> [Accessed 8 May 2009].
- Sharma, N., 2002. *Still missing out? Ending poverty and social exclusion: messages to government from families with disabled children*. Ilford: Bernardo's.
- Shaw , M., 2007. *What is Genocide*. Cambridge: Polity Press.
- Shaw, I., 2008. *Ethics and the Practice of Qualitative Research*. *Qualitative Social Work*. 7 (4), pp. 400-414.



- Shklarov, S., 2007. Double Vision Uncertainty: The Bilingual Researcher and the Ethics of Cross –Language Research. *Qualitative Health Research*, 17 (4), pp. 529-538.
- Silver, H. & Miller, S. M., 2002. *Social Exclusion: The European Approach to Social Disadvantage*. Washington DC: Poverty and Race Research Action Council.
- Silverman, D., 2004. Research and Social Policy. In: C. Seale, ed. 2006. *Researching Society and Culture*. 2<sup>nd</sup> ed. London: SAGE Publications. Ch. 6.
- Sloper T. & Beresford, B., 2006. Editorial: Families with disabled children. *British Medical Journal*, 333 (7575), pp. 928-929.
- Sotiropoulos, D. & Pop, L., 2007. Bulgaria and Romania. In: B. Deacon & P. Stubbs, eds. 2007. *Social Policy and International Interventions in South East Europe*. Cheltenham: Edward Elgar Publishing Limited. Ch. 4.
- Sotiropoulou, V. & Sotiropoulos, D., 2007. Childcare in Post-Communist Welfare States: The Case of Bulgaria. *Journal of Social Policy*, 36 (1), pp. 141-155.
- Stanciulescu, E., 2010. Children and Childhood in Romanian Society and Social Research Ideological and Market Biases and some Notable Contributions. *Current Sociology*, 58 (2), pp. 309-334.
- Steinke, I., 2004. Quality Criteria in Qualitative Research. In: U. Flick., E. von Kardorff & I. Steinke, eds. 2004. *A Companion to Qualitative Research*. London: SAGE Publications Ltd. Ch.4.7.
- Stokes, G., 1993. *The walls came tumbling down: the collapse of communism in Eastern Europe*. New York: Oxford University Press, Inc.
- Stone, E. ed., 1999. *Disability and Development: Learning from action and research on disability in the majority world*. Leeds: The Disability Press
- Stone, E. & Priestley, M., 1996. Parasites, pawns and partners: disability research and the role of non-disabled researchers. *British Journal of Sociology*, 47 (4), pp. 699-716.
- Stubbs, P., 1999. From Pathology to Participation?: Reflection on Local Community Development in Bosnia and Croatia and Prospects for the Future. *Journal of Social Work Theory and Practice*, Issue 1, year 1998/1999; Bemidji State University, Bemidji: Minnesota, USA.
- Stubbs, P., 2006. *Civil Society or Ubleha*. Available at: <http://www.nenasilje.org/publikacije/pdf/20poticaja/20pieces-stubbs.pdf> [Accessed 5 June 2009]
- Stubbs, P., 2007. *International Organizations and Child Care System Reform in South East Europe-Draft*. Final report for UNICEF. The Institute of Economics Zagreb.

- Stubbs, P., 2008. *A Missed Opportunity?: social and labour market policies in the Western Balkans*. Available at: <http://paulstubbs.pbworks.com/f/Social+Region+Stubbs.pdf> [Accessed 24 March 2009]
- Swain, G. & Swain, N. 2003. *Eastern Europe since 1945*. 3<sup>rd</sup> ed. Hampshire: Palgrave, Macmillan.
- Szasz, T., 1983. *Ideology and Insanity: essays on the psychiatric dehumanisation of man*. London: Marion Boyars.
- Taylor, S., 1998. Leaving the Field: Research, Relationships and Responsibilities: In: A. Bryman & R. Burgess, eds. 1998. *Qualitative Research, Volume IV*. London: Sage Publication. Ch. 82.
- Taylor, S. & Bogdan, R., 1998. *Introduction to qualitative research methods: A guidebook and resource*. 3<sup>rd</sup> ed. New York: John Wiley & Sons.
- Teegan, H., Doh, J. & Vachani, S., 2004. The importance of nongovernmental organization(NGOs) in global governance and value creation: an international business research agenda. *Journal of International Business Studies*, 35 (6), pp. 463-83.
- Temple, B., 1997. Watch Your Tongue: Issues In Translation and Cross-Cultural Research. *Sociology*, 31 (3), pp. 607–618.
- Temple, B. & Edwards, R., 2002. Interpreters/translators and cross-language research: Reflexivity and border crossings. *International Journal of Qualitative Methods*, 1 (2), pp. 1-22.
- Temple, B., and Young, A., 2004. Qualitative research and translation dilemmas. *Qualitative Research*, 4 (2), pp. 161-178.
- The Centre for Studies on Inclusive Education, 2002. (CSIE) - *Inclusion Information Guide*. Sharon Rustemier, April 2002.
- The Regional and Environmental Centre for Central and Eastern Europe, 2009. *Map of Central and Eastern Europe*. Available at: [http://archive.rec.org/REC/Maps/eur\\_map.html](http://archive.rec.org/REC/Maps/eur_map.html) [Accessed 25 December 2010]
- Thomas, C., 2001. Feminism and disability: The Theoretical and Political Significance of the Personal and the Experiential. In: L. Barton, ed. 2001. *Disability, Politics & the Struggle for Change*. London: David Fulton Publishers. Ch.5.
- Thomas, C., 2004. Developing the Social Relational in the Social Model of Disability: a theoretical agenda. In: C. Barnes & G. Mercer, eds. 2004. *Implementing the Social Model of Disability: Theory and Research*. Leeds: The Disability Press. Ch. 3.

- Thompson, M., 1992. *A Paper House: The Ending of Yugoslavia*. New York: Pantheon Books
- Tisdall, K. & Liebel, M., 2008. Children's participation in decision-making: Exploring theory, policy and practice across Europe. *Scientific Report ESF Exploratory Workshop*. European Science Foundation.
- Tobis, D., 2000. *Moving from Residential Institutions to Community- Based Social Services in Central and Eastern Europe and the Former Soviet Union*. Washington DC: The World Bank.
- Todorova, M., 1997. *Imagining the Balkans*. Oxford: Oxford University Press.
- Todorova, E., 2000. *The Neighbourhood Centre: new strategy for survival in Bulgaria, Bemidji State University and Inter-University Centre*. Available at: [http://www.bemidjistate.edu/academics/publications/social\\_work\\_journal/issue01/pdf/todorova.pdf](http://www.bemidjistate.edu/academics/publications/social_work_journal/issue01/pdf/todorova.pdf) [Accessed 10 November 2009].
- Todorova, V., 2009. Children's rights in Bulgaria after the end of Communism. *The International Journal of Children's Rights*, 17 (4), pp. 623-646.
- Tonkiss, F., 2006. Using focus groups. In: C. Seale, ed. 2006. *Researching Society and Culture*. 2<sup>nd</sup> ed. London: SAGE Publications. Ch. 15.
- Traustadóttir, R., 2007. Rethinking Disability and Impairment. *Disability & Society*, 22 (2), pp. 213-217.
- Tsokova, D. & Becirevic, M., 2009. Inclusive education in Bulgaria and Bosnia and Herzegovina: policy and practice. *European Journal of Special Needs Education*, 24 (4) pp. 393 – 406.
- Twinn, S., 1997. An exploratory study examining the influence of translation on the validity and reliability of qualitative data in nursing research. *Journal of Advanced Nursing*, 26 (2), pp. 418-423.
- UN Enable, 2008. Rights and Dignities of Person with Disabilities. Convention in Brief. Available at: <http://www.un.org/disabilities/> [Accessed 25 November 2009]
- UNDP, 2000. *Social Assessment of Child Care in Bulgaria*, UNDP, UNDESA, The World Bank, Sofia.
- UNDP, 2008. *Pension reform and social protection systems in Bosnia and Herzegovina*. UNDP.

UNDP, 2009. *Human Development Report: Overcoming barriers, human mobility and development*. UNDP

UNICEF, 1999. *Women in Transition*, MONEE, Regional Monitoring Project Report, No 6. International Child Development Centre, Florence, Italy

UNICEF, 2003. *Legal Aspects of Social Protection for Children in Bosnia and Herzegovina*. UNICEF

UNICEF, 2003b. *Children and Institutions in Bosnia and Herzegovina, First Report Capacity Building Research: Unaccompanied Children and Children at Risk of Being Institutionalized in Bosnia and Herzegovina*. UNICEF.

UNICEF, 2005. *Children and Disability in Transition in CEE/CIS and Baltic States*, Florence: Innocenti Research Centre.

UNICEF, 2007. *Promoting the Rights of Children with Disability*, Innocenti Digest, No 13. Florence: Innocenti Research Centre.

UNICEF, 2007b. United Nations Children's Fund. *Education for Some More than Others- A regional study on education in central and Eastern Europe and the Commonwealth of Independent States CEE/CIS*. Florence: Innocenti Research Centre.

UNICEF, 2007c. *Draft. Child Care System Reform Efforts: Country Examples from South East Europe*. UNICEF.

UNICEF, 2010. *Situation Analysis: Inclusive Education in CEE/CIS*. UNICEF CEE/CIS Regional Office. Geneva: UNICEF.

United Nations, 1989. *Convention on the Rights of the Child*. United Nations.

United Nations, 2006. *Convention on the Rights of Persons with Disabilities*. United Nations.

United Nations, 2009. *United Nations Children's Fund: Draft Country Programme Document, Bulgaria*. Presented to the Executive Board, Annual Session 2009. United Nations.

United Nations. 2010. *Monitoring the Convention on the Rights of Persons with Disabilities Guidance for human rights monitors. Professional training series No. 17*. New York and Geneva: United Nations.

United Nations Economic Commission for Europe 2008(UNECE). *Infant Mortality Rate by Sex, Country and Year*. Available from:  
[http://w3.unece.org/pxweb/Dialog/varval.asp?ma=003\\_GEHEInfantDeath\\_r&ti=Infant+Mortality+Rate+by+Sex%2C+Country+and+Year&path=../DATABASE/Stat/30-GE/06-Health/&lang=1](http://w3.unece.org/pxweb/Dialog/varval.asp?ma=003_GEHEInfantDeath_r&ti=Infant+Mortality+Rate+by+Sex%2C+Country+and+Year&path=../DATABASE/Stat/30-GE/06-Health/&lang=1) [Accessed 23 March 2010]

University of Tuzla, 2007. *Faculty of Education and Rehabilitation: Curriculum for undergraduate studies in defectology*. Tuzla: University of Tuzla.

USAID, 2008. *Social Work Educational and the Practice Environment in Europe and Eurasia; Social Transition Team*. Office of Democracy, Governance and Social Transition of the United States Agency for International Development, Inc. USAID

Vann, B. & Šiška, J., 2007. From 'cage beds' to inclusion: the long road for individuals with intellectual disability in the Czech Republic. *Disability & Society*, 21(5), 425-439.

Vygotsky, L.S., 1993. *The Collected Works of L.S. Vygotsky: Volume 2*. (Chapters originally published between 1924-1935). New York: Plenum

Wagener, H., 2002. The Welfare State in Transition Economies and Accession to the EU. *West European Politics*, 25, (2), pp. 152 – 174.

Waldrop, D., 2004. Ethical Issues in Qualitative Research with High- Risk Populations. In: D. Padgett, ed. 2004. *The Qualitative Research Experience*. Belmont: Thomson-Brooks/Cole.

Wall, J., 2008. Human Rights in Light of Childhood. *International Journal of Children's Rights*, (16) 523–543.

Walmsley, J., 2006. Ideology, Ideas and Care in the Community, 1971-2001. In: J. Welshman & J. Walmsle, eds. 2006. *Community Care in Perspective: Care, Control and Citizenship*. London: Palgrave Macmillan

Walsh, D., 2006. Doing ethnography. In C. Seale, ed. 2006. *Researching Society and Culture*. 2<sup>nd</sup> ed. London: SAGE Publications. Ch. 17.

Watson, N., 2004. The Dialectics of Disability: a social model for the 21st Century? In: Barnes, C. & Mercer, G. eds. 2004. *Implementing the Social Model of Disability: Theory and Research*. Leeds: The Disability Press. Ch. 7.

Ward, L. N., 2009. Social Exclusion, Social Identity and Social Work: Analysing Social Exclusion from a Material Discursive Perspective. *Social Work Education*, 28 (3), pp. 237 – 252.

Waren, L. & Boxall, K. 2009. Service Users In and Out of the Academy: Collusion in Exclusion? *Social Work Education*, 28 (3), pp. 281 – 297.

Wengraf, T., 2001. *Qualitative Research Interviewing*. London: Sage Publication.

Westcott, H. & Cross, M., 1996. *This Far and No Further: towards ending the abuse of disabled children*. Birmingham: Venture Press.

Wolfensberger, W., 1972. *The Principle of Normalisation in Human Services*. Toronto: National Institute on Mental Retardation.

Woodward, S., 1995. *Balkan Tragedy-Chaos and Dissolution After the Cold War*. Washington DC: The Brookings Institution.

World Bank, 2008. *Report No: 38604-BG Project Appraisal Document on Proposed Loan to the Republic of Bulgaria for a Social Inclusion Project*. World Bank.

World Bank, 2009. *Report No: AB4773. Social Safety Nets & Employment Support Project Information document (PID) project stage*. World Bank.

Yates, S., Dyson, S. & Hiles, D., 2008. Beyond normalization and impairment: theorising subjectivity in learning difficulties-theory and practice. *Disability & Society*, 23 (3), pp. 247-258.

Young, A. & Ackerman, J., 2001. Reflections on Validity and Epistemology in a Study of Working Relations between Deaf and Hearing Professionals. *Qualitative Health Research*, 11 (2), pp. 179-189

Young, E. & Quinn, L. 2002. *Writing Effective Public Policy Papers- A Guide for Policy Advisers in Central and Eastern Europe*. Budapest: Open Society Institute.

Ytterhus, B., Wendelborg, C. & Lundeby, H., 2008. Managing turning points and transitions in childhood and parenthood-insights from families with disabled children in Norway. *Disability & Society*, 23 (6), pp. 625-636.

Zavirsek, D., 2008. Engendering Social Work Education under State Socialism in Yugoslavia. *British Journal of Social Work*, 38 (4), pp. 734–750

Zarb, G., 1997. Researching Disabling Barriers. In: C. Barnes & G. Mercer, eds. 1997. *Doing Disability Research*. Leeds: The Disability Press. Ch. 4.

Ziebland, S. & McPherson, A. 2006. Making sense of qualitative data analysis: an introduction with illustration from DIPEX (personal experience of health and illness). *Medical Education*, 40 (5), pp. 405-414.

Zouev, A. ed., 1999. *Generation in Jeopardy: Children in Central and Eastern Europe and the Former Soviet Union*. New York: UNICEF and M. E. Sharpe, Inc.



Appendix 1a-Information sheet –also provided in Bosnian and Bulgarian language

## PARTICIPANT INFORMATION SHEET

You are being invited to take part in the **A Qualitative Study of Children with Disabilities and their Families in Eastern Europe**. It is important that you understand why research is being done and what it involves, so please take time to read the following information.

This research is about situation for disabled children and their families in Eastern Europe. To find out this the focus groups and interviews will be held with disabled children, their parents and people who work with disabled children, as well as people who are in position of making policies. Children are very important in this research because this study is mostly about children and children's stories and children's views will be treated with great respect and appreciation.

In 2007/2008 the researcher Majda Becirevic is planning to conduct interviews in Bosnia and Herzegovina and Bulgaria with people who work with disabled children; doctors, teachers, pedagogues, defectologists, psychologists and social workers. The group talks will be held with disabled children, but if a child doesn't feel comfortable talking in the group the talk can be done privately. The group talks will last approximately between 1-2 hours. Individual interviews will last between half and one hour. The group talks and individual interviews will be audio taped if participants agree.

Everything that participants say during this research will be treated as confidential information and no names will be mentioned in any publication that comes out as result of this research. When we finish the interview if you change your mind and tell me you don't want me to use information that will be ok. In any case I will be happy that I talked to you.

This research has been approved by the Open University Human Participants and Materials Ethics Committee. The idea of this research is make your voice heard and to use it in advocating for change. If you have any questions about the research or if you have comments or suggestion please contact me:

Majda Becirevic  
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If participant wish to speak with someone else about the research  
my supervisor professor Monica Dowling from the Open University can be reached on  
+44(0)1908 659317 and e-mail [m.s.dowling@open.ac.uk](mailto:m.s.dowling@open.ac.uk)

**The researcher: Majda Becirevic** has a degree in psychology and master degree in inclusive and special education. She worked in Bosnia and Herzegovina on promotion and protection of children's rights for several years. Currently she is a full time PhD student at the Open University in England conducting research on children with disabilities and their families in Eastern Europe.



Appendix 1b: Informed consent- provided in Bosnian and Bulgarian language  
and signed by all participants.

INFORMED CONSENT

We are inviting you to take part in **A QUALITATIVE STUDY OF CHILDREN WITH DISABILITIES AND THEIR FAMILIES IN EASTERN EUROPE**. If you agree to participate, you will be asked set of questions about your work (for parents: life with disabled child) with or for disabled children and about your opinions on disability policies and practices.

We want to assure you that all answers will remain confidential. All data will be kept in a locked file cabinet in a secured place. Access will be limited to the researcher and researcher's supervisors only. Every person participating will be assigned pseudonym in order to protect privacy. No information about your answers or this interview will be provided to anyone.

Participation in this study is voluntary. If, for any reason you change your mind about your participation the interview can be discontinued without any consequence. If after the interview you wish to remove your data or if you have any questions about this study please contact Majda Becirevic on: Phone in the UK: +44(0)1908 33 22 57 or in B&H +38733451326 or at [m.becirevic@open.ac.uk](mailto:m.becirevic@open.ac.uk). The request for data removal will be taken until 31<sup>st</sup> of March 2009.

Your participation in this study is much appreciated. Thank you.

I AGREE \_\_\_\_\_ DO NOT AGREE \_\_\_\_\_ to participate in this study.

I prefer researcher to use AUDIO RECODING \_\_\_\_\_ TAKE NOTES. Please circle one.

Signed \_\_\_\_\_

Date \_\_\_\_\_

Profession \_\_\_\_\_

If you would like a copy of any publication resulting from these data, please provide your address.  
Keep in mind that work like this can take up to few years.

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



## Appendix 2: List of interviews in Bosnia and Herzegovina and Bulgaria

### Bosnia and Herzegovina

Place and date of interviews	Place of work	Position	Method-description
Sarajevo, July 2007	International organisation	Project officer	Interview
Sarajevo, July 2007	B&H national NGO	Organisation director	Interview
Sarajevo , July 2007	University hospital	MD-paediatrician	Interview
Sarajevo, July 2007	Centre for social work Sarajevo	3 Social workers	Group interview
Breziljek, July 2007	Residential Institution	Defectologist	Interview
Breziljek, July 2007	Residential Institution	Pedagogue	Interview
Sarajevo, disability conference, November 2007	Ministry of social affairs Republika Srpska	Deputy minister	Interview
Sarajevo, disability conference , November 2007	Ministry of social affairs Republika Srpska	Defectologist-advisor	Interview
Sarajevo, November 2007	Special school for children with intellectual disabilities	Defectologist	Interview
Sarajevo, November 2007	Special school for blind children	Principal	Interview
Banja Luka, November 2007	Parents' association-local NGO	President	Interview

Banja Luka, November 2007	Parents' association-local NGO	Manager	Interview
Banja Luka, November 2007	Pedagogical institute of Republika Srpska	Advisor for preschool education	Interview
Banja Luka, November 2007	National NGO-watchdog role	Officer-psychologist	Interview
Banja Luka, November 2007	National Disability NGO	Spokesperson	Interview
Sarajevo, November 2007	International NGO	Country manager	Interview
Banja Luka, December 2007	Centre for Social Work	Director	Interview
Banja Luka, December 2007	Parents-mothers	9 mothers	Focus group
Village Middle Bosnia, December 2007	Mother and son	Family	Interview
Sarajevo, December 2007	Mother and son	Family-foster care	Interview
Zavod Breziljek, January 2008	Residential institution	Resident/child	Interview
Zavod Breziljek, January 2008	Residential institution	Resident/child	Interview
Zavod Breziljek, January 2008	Residential institution	Resident/child	Interview
Zavod Breziljek, January 2008	Residential institution	Resident/child	Interview
Zavod Breziljek, January 2008	Residential institution	Teacher-defectologist	Interview

Zavod Breziljek, July 2008	Residential institution	Manager	Interview
Zavod Breziljek, July 2008	Residential institution	Art therapist	Interview

## Bulgaria

Place and date of interviews	Place of work	Position	Method
Sofia , May 2008	International organization	Project officer- social policy and planning	Interview
Sofia , May 2008	State agency for social assistance	Director and Deputy executive director	Group interview
Sofia, May 2008	Family	Disabled woman activist and her family	Group interview
Sofia , May 2008	National NGO- humanitarian organization	Social Policy Officer	Interview
Sofia, May 2008	Bulgarian national disability NGO	Executive director	Interview
Sofia, May 2008	University	University professor and former government policy maker	Interview
Sofia, May 2008	Parents' organization- Centre for rehabilitation and integration of children with autism, Sofia	Centre managers, and therapists – both parents	Group Interview
Sofia, May 2008	Day care centre Pokrov Foundation	Logoped and coordinator	Interview
Sofia, May 2008	International NGO	Sociologist	Interview

Place and date of interviews	Place of work	Position	Method
Sofia, June 2008	Sofia University	Lecturer in special needs education	Interview
Sofia, June 2008	A family	Grandmother (primary carer) and granddaughter	Group interview and play
Sofia, June 2008	Ministry of Education-special needs unit	Director	Interview
Sofia, June 2008	Centre for Autism	3 mothers	Focus group
Sofia, June 2008	Pokrov foundation	3 mothers and one father	Focus group
Sofia, June 2008	International organisation	Researcher	Interview
Kranevo, October 2008	Kranevo special residential school	Principal interview	Interview
Kranevo, October 2008	Kranevo special residential school	2 teachers talk+ visit to classrooms	Group interview
Varna, October 2008	Day centre for children with learning disabilities	Director	Interview
Varna, October 2008	Integration Centre for young people	Director	Interview

### Appendix 3: Interview excerpt

Interviewee with Logoped (coordinator) – Bojana -pseudo name

Day Centre, Sofia

Translator Marriella Pantcheva

Sofia- 15th May 2008

Interviewer Majda Becirevic

Duration 59 mins

Yellow highlights are codes and text in red are associated themes and interpretation

Marriela and I introduced Bojana with the research and explained ethical issues. Bojana said that she doesn't have statistics and she was worried that she will not be a good informer. I explained that that is ok, because this is a qualitative research looking into views of people.

Majda: Can you just say little bit about the centre. What do you do in this centre?

Bojana: of course, but I may also give you internet site of the centre and there is lot of information. This is a project of Bogorodicen Foundation. Pokrov Bogorodicen is big foundation that has project in different spheres. Our project is training, education, integration and reintegration of children with disabilities. And now we are expanding out activities among young people. We are not financed by the government... we are not financed by the government budget. The project was financed by sponsored from Germany for the first three years. (time on the tape -3,40). Financing and international influence

Since 2006 Pokrov foundation has provided the premises and we have been getting some money from private donors and we also contribute some money which we get

from successful project. Other resources we get from private donors, business, projects, companies and some money from Pokrov Foundation- Financing.

Initially all the money was from Pokrov Foundation and now we are successful in finding money alone and in managing things ourselves. - Sustainability

Of course we received some money from government organisations after applying...but only project work, -lack of commitment by the government? for few months and that was for additional activity for the children.

People find out about is because there is information on internet and we are let's say well known. People and professionals from the medical establishments, like children's psychiatry and children's neurology clinics send their parents and children here. They give information about us and that is how children come here- referral mechanism

7.27

also children are coming here from other centres. We are communicating with each other- cooperation. There are not so many day centres. Lack of day centres

The main things which we do depend on child's needs- mention of needs but no mention of child's rights. ... what is his or her situation, what are the main problems, what the parents want for the child.- parents' wishes.

And what we can provide to them, that is the most important thing. That is very important for the communication, because the child's needs can be communicated to special schools and therapies.



We work with several universities, they send their students here and they do speech therapy, psychology, they teach something and network is expanding.- cooperation

Some of the universities don't pay for training placements and some pay, it depends what we have negotiated. If the university doesn't have money to pay for the training students are working mainly with the children and they have been of course advised by the specialist here and if the university has some money or some has been negotiate, the university pays for the centre specialist and that person trains students. 11.45

how do we work when parents come here with the child-we require from them to provide some documents, documentation about situation of the child and of course we listen what do they say about the child. – listening to parents, but no mention of communicating with disabled children. We should have some initial information about the child. We do an interview. Then the child gets examined by the speech therapist, psychologist and the pedagogue. And it takes little bit time, depending on individual child. Some children need 2-3 interviews and after the interviews are completed we decide what to do with this particular child. Decisions made by professionals and parents, children's wished not mentioned.

Than individual program is made for every child here in the centre 14.15. individual programme - this individual program contains details on the health status of the child, also analysis of the speech therapist, pedagogue, and by the psychologist and it contains detailed information about learning skills of the child and detailed information what the objectives are and the activities with the particular child with

educational activities' and other activities, like sport, or art classes and computers skills. The program is for one year and it can be developed and mended in accordance with changes which can happen with the child. 16.25

The idea is to work one year with the child and to try to integrate that child, for example here in the groups or other opportunity to integrate it to mainstream school. We work with several mainstream schools and several private schools. If that is possible we want to integrate child into mainstream school. It depends entirely on the child. Integration depending on the child-focus is on changing the child-normalisation. Some children go once a week for two hours. Others go 3-4 times a week for several hours. We have children who go half a day to ordinary school and in the afternoon they come here to us. It varies. **Different models of 'integration'.**



### INSTITUTIONS

#### Professionals in institutions (pedagogues, rehabilitators, defectologists)

- What is the role of this institution in the lives of disabled children?
- How do children get here?
- What is your role in professional sense?
- Is it better for children to be here or in their families?
- What happens with children when they reach 18? Stay in institution?
- Vocational training opportunities.
- Independent living opportunities.
- People with disabilities and decision making.
- What support is provided for the families?
- Respite care opportunities.
- Education opportunities-mainstream or special?
- Structural barriers. What are they in your opinion?
- Opportunities to work in an open market or sheltered workshops?

#### Children in institutions

- When did you come to live here?
- How do you find it? Like it or not? What do you like about this place?  
Something that you didn't like?
- Do you have friends here?

- What would you like to do when you get older? Do you like to stay here or move somewhere else?
- What do you do in your free time?
- Do you like school here?
- Is there anything you would like to change?
- Do you have friends outside this place?
- How do you get on with the staff here?
- Do you have privacy here?
- If you want to go out. How is that organised?
- If you don't like something is there anyone you can talk to?
- What about your things, clothes. Who takes care of that?

## **COMMUNITY and professionals in the community**

### **NGO workers**

- What does your organisation do for disabled children? What sort of support do you provide? Do you have any partnerships - cooperation's with municipality, local NGOs, international NGOs?
- How did you get involved in work around disability?
- Does your organisation have philosophy or mission statement about disability.
- What are the issues that disabled children are faced with in B&H/Bulgaria?
- What are the issues for the family?
- What do you think about educational opportunities?
- Have things changed for disabled children in the last 12 years? How?
- What do you think still needs to be changes and how?

## Professionals:

- How is disability diagnosed in B&H/Bulgaria?
- What do you suggest to parents once diagnosis is made? Do you then do a follow up with the same child? Do you give them advice about care, education?
- How is assessment made for pension or child allowance?
- Are parents advised to send children to institution?
- What rehabilitation is on offer? Is it available? Free?
- What is the role of social worker / defectologist/pedagogue/medical doctor/teacher in issues around a disabled child?
- Are you part of categorisation commission? How does that work?
- What support is provided for a child?
- What support is provided for the family?
- On the basis of what support is decided? (Needs or right of the child?) Who decides? Do you ask child what he/she needs? Do you ask parents?
- Do you do family visits? In which situations?
- Do parents and children come here?
- Are you more in favour of children with disabilities living at home or living in institution?

## FAMILIES

### Children living with the family

- What do you like doing?
- Do you like your school?
- Do you have friends in school?
- Do you hang out with them after school? Do you go to their homes?
- Do you have friends in your neighbourhood?
- What would you like to do when you get older?
- How do you go to school?
- Are you involved in any after school activities?

### Parents

- What support do you receive from the government?
- Are you involved in work of NGOs?
- Are you involved in policy making?
- Do you work? How do you organise yourself with work and care for your child?
- Does your child go to school? Which school? How did you decide to enrol him/her in this school? What is your experience of his education?
- What is it like to have a disabled child in B&H/Bulgaria?
- Where did you learn about his/her impairment?
- Does anyone help you with the child care? How? How often? What do they do? What about other family members, your parents, cousins?

- Did you consider opportunities for his/her further education?
- What do children's rights mean for you and your child? Do you know what rights your child has?
- What rights do you have as a family?
- What is your experience with doctors, pedagogues, teachers?
- In your opinion how are disabled children accepted in community, society?
- What change would you like to see happening?

## POLICY MAKERS

### Government policy maker

- What is the government policy for disabled children in B&H/Bulgaria?
- What support/benefits are offered to disabled children and their families? How does this work? Do you think this support is sufficient? Who gives support?
- How does the government decide on amount of support?
- Are there any special provisions for employed parents? Childcare?
- How do you go about developing policies? Who do you consult with?
- Do you model policies on some other country?
- What is the role of the EU?
- In your opinion, to what extent disabled children can be included in society?
- Is there any particular philosophy behind government decisions about disabled children and their families?

## International organisations/International NGOs/National and local NGOs

- What your organisation does in the field of disability?
- How do you see the situation for disabled children and their families in B&H/Bulgaria?
- Do you participate in policy making? If yes, how?
- What opportunities children with disabilities have in B&H/Bulgaria? What they do not have? Do you know why?
- Where did you learn about disability? Does your organisation have training programmes for disability?
- What do you think needs to be changed?
- Who is the most responsible for funding in relation to disability?

## Appendix 5: An example from the fieldwork diary

22<sup>nd</sup> October 2008.

**Kranevo, Bulgaria- residential school for children with intellectual disabilities**

Sunny day in Bulgarian seaside resort of Varna, a modern town with plentiful investments compared to rest of Bulgaria. Luba (the interpreter) says it's busy with people during summer season, but now it appears quiet. Few weeks previously we arranged to visit school for children with intellectual disabilities in the town near Varna. Arranging the visit and interviews took some convincing and Luba had to pull in connections with her friends in Varna who vouched for us with the school principal. Friend of a friend called the school principal and explained what we want to do. This gave me almost no control of the whole situation and since favours were being done I was not able to make special requests for interview conditions. Few days before we are due to go to the school I suggest Luba calls the principal to confirm it will be OK to speak to children and to ask her if someone can help us set up the interviews. Luba said the principal wasn't too happy and said interviews with children are too difficult to organize. Still, at this stage, I was hanging on to little bit of hope that this will be possible....

The school looked bit old from the outside and very quiet. There was no one in the playground. We were early and a porter shown us to principal's office. We sat on sofa outside her office prepared to wait, but she appeared soon and said it is OK to start early. She seemed very keen to start talking and immediately got into stories about school and what they do there. After some time I realized that she had her agenda; to promote her school and to convince us to give some money for the school. She asked us about possibility for doing projects together. It did not take long to realize she was against inclusion and social integration. She openly said that for children with intellectual disabilities or '*oligophrenia*' as she called it, inclusion is impossible. After seeing boys outside and few children on the corridor I was under impression that they were not disabled, so without mentioning that, I asked her how many disabled children you have in the school and she said defensively they are all disabled.

She said she will take us around to some classrooms but asked us politely and firmly not to ask children anything because they will be distressed if we try to speak to them. Her request was quite firm, so we observed from the door. Children looked at us. There were 10-12 of them, many Roma, curious about us, but quietly sitting at their little tables. The classroom was small and stuffy, with old fashioned desks and chairs. The teacher was sitting in the front facing children, one small boy was in her lap. The principal tells us that he is very disabled and that teacher has to hold him in her lap. The second classroom was similar. We didn't speak a word to children, there was no chance. When we came back into her office she repeated several times how severely disabled these children are and that they cannot say much, some of them only 10 words, some cannot even say their name.



During the interview we were interrupted few times with people coming into her office and asking her to open a classroom for them or some cupboards. When she popped out to unlock these rooms Luba pulled a face and whispered to me: *'She holds all the keys'*. I loved this sharp remark. To me it was a symbolic reflection of atmosphere in the school....

Later, the principal introduced us to two teachers in the school, who kept confirming director's opinion. One of them openly said how much she is against integration. For her that is impossible. She said inclusion is being forced, but very unsuccessfully. Children are neglected by teachers in mainstream schools and teased by their peers. She proceeded to say: *'When they see it is not working for disabled children in the mainstream they will open special class again and then resort to special school. This now is pointless, history will be repeated'*. I wanted to contradict and enter into debate with them but remembered it was not my role.

After interviews with principal and two members of staff we eventually left the school. We waited at the bus stop for a long time, both of us quiet. We agreed that this school was not physically bad and it was not too far from the town. However the atmosphere in the school was undemocratic, controlling and we felt that the principal wanted to impose her power on us, by constantly reminding us what we may and may not do. It left us feeling frustrated and manipulated. However this was daily reality for children in the school. We waited and waited and then the bus finally arrived, but it did not take us far. Not easy to leave this place.

## Appendix 6 OSOP strategy for analysing data

This OSOP shows analysis for the topic family life. Other OSOPs included data on institutions, professionals and policy making. Italics are exacts quotes, the rest of texts are summaries of the codes.

Themes	Codes
Ambivalence towards child's disability	Trying many cures and therapies, faults of medical doctors, <i>'delivery not performed well', 'he would be normal if the doctors had not made mistake', 'he did not get enough oxygen at birth', 'doctors were negligent'....</i>
Importance of diagnosis	Mother's claimed doctor's lack of knowledge- <i>'how that come that doctors did not recognise impairment straight away'</i> , told diagnosis in hurtful way, confusion about diagnosis, not enough information, poor communication with doctors- <i>'they said he will be handicapped forever'</i> , feelings of personal failure and inadequacy, tragedy discourse used by professionals in communicating diagnosis
Caring is a woman's job	Only one father attended focus groups, <i>'fathers rarely come to association activities, 'he just left after birth', 'after while he stopped calling', 'I have good marriage but in some things I am alone', 'if they stay with the family father's work and provide financial support'</i> , mothers provide extensive complex care, <i>'relatives do not always provide support for disabled children'</i>
Mothers advocating	Fighting for rights, social benefits, some speaking on television, establishing associations, trying to convince authorities to improve provisions, <i>'we want to use your research for our advocacy'</i> .
Relationships in a family	<i>'my relatives turned back on me', 'disabled children are treated differently by grandparents', relatives do not know how to care for disabled child</i> , some grandparents provide extensive help with care, <i>'siblings often take part in providing care', 'siblings sometimes receive less attention', 'siblings can become more responsible and better able to understand diversity'</i> , warm and caring relationships with parents and carers
Prejudices	<i>'People stare at us', 'children avoid playing with her', he was bullied in school', 'our birthday parties are only attended by other disabled children and their parents', 'no friendships with non-disabled children'...</i>
Predominantly bad relationship with practitioners	Lack of information, <i>'doctors are kind but often not able to help', 'he gave him sedatives which made him worse, 'we have to wait in GP's surgeries for a long time'</i> , bureaucratic and insensitive approach of social workers, <i>'social workers never visit us at home'</i> , professionals do not treat parents as partner, several examples of helpful professionals...
Accessing services	Exclusion from education, hurtful experiences with disability assessments/commissions, <i>'there is no support without categorisation', slow renewals and high costs of disability assessments, 'they gave percentage of how damaged he is', 'dentists refuse to treat child with intellectual disabilities or epilepsy'...</i>
Finances	High cost of therapies, medication, spas, loss of earning, problems in claiming disability allowance, increase in disability allowance in one part of BiH, personal assistance, free transport in Bulgaria, employers' lack of understanding, personal assistance scheme not well designed...
Diverse families	Families in rural areas with poor transport and no services, positive experiences of foster family, lack of understanding for grandparents' as carers, some parents had to move house to access services...
Participation	Disabled children do not participate, parents and practitioners decide what is best for a child, children are never asked, and services do not include children in any developments...
Parents suggested	Increasing financial support for families, counselling, individually adjusted packages for diverse families, policy makers considering perspectives from parents, need to improve transport, increasing numbers of day centres, improving inclusive education, increasing inclusive early childhood care options, raising awareness of public and professionals.

## Appendix 7: Translation of institutional songs- Zavod Breziljek

### Song 1

'There is a love sadness and happiness in this house, like anywhere else; the sun is yellow, the sky is blue, here the spring is fragrant too. This is my house here I live this is my house, only one for me'.

Can you see me like a bird my friend, in my mind I often fly over the wire; my thoughts carry me, I want to fly, in my family home to land for a moment'.

### Song 2:

'Under the same sky we were born, but your star might be brighter than mine, my heart is full of love, for all people like you and me. Come, on be my friend, I am same like you; look I am giving you my hand, embrace it; I often travel on tracks of dreams, easily I drift into imagination; my life is different and you think why.

### Song 3:

'Morning wakes sleepy pupil; carer calls him instead of mother, she calls him with the gentle smile, the school bells he will hear soon. The children's buzzing is everywhere, smell of fresh bread and hot tea, rattle of plates, spoons and cups, it's pretty this house of ours; When the night comes and darkness and falls children's sleep comes over us, quite and daring, like from the tale the face of mother comes to us (appears before our eyes)'.

### Song 4:

'Big as the world, shone on by rapturous sun, nobody is more orphan than me my dear mother. Father I don't have, mother I don't have, no family anywhere, only betraying woman, the dear God will judge her. If my mother was alive she would comfort me, but my old mother is covered by green grass'.